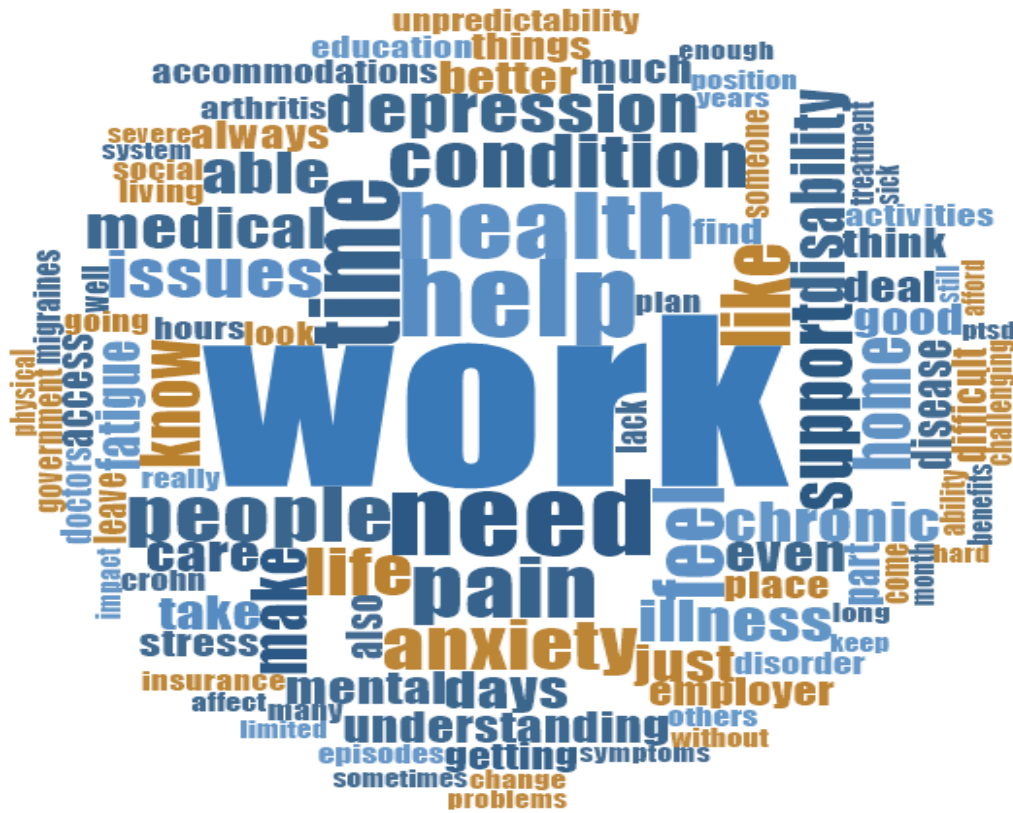


PEOPLE
WITH
EPISODIC HEALTH CONDITIONS
SPEAK OUT ABOUT



Final Report
for
Employment and Social Development Canada

Contract # 4500000378

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*Funding for this publication was provided by the Office
for Disability Issues, Employment and Social
Development Canada.*

*The opinions expressed in this document are those of the author and do not necessarily reflect the views of
Employment and Social Development Canada.*

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Executive Summary

Background

1. 953 Canadians who are living with an episodic health condition *spoke out* about the impact that their health condition has on their life choices and their lives. The research team acknowledges that this sample is not representative of the population with episodic health conditions in Canada. However, these respondents have provided a rich, contextualized understanding of what it means to live with an episodic health condition and their insights add to the knowledge base of this population.
2. This survey is the third activity of Phase I of a larger research project titled “Learning from Each Other”. This three-phase project has, as its focus, improving our understanding of the employment needs of people with episodic disabilities. The goal is to produce resource materials that will be used to increase the hiring and retention of persons who have episodic health conditions.

Methodology

3. Organizations and associations that represent the selected health conditions informed their members about the research, indicated their support of the initiative and encouraged those individuals with the lived experience to complete the questionnaire. Members of the research team also used their networks and social media to contact potential respondents.
4. Respondents were asked to share the knowledge of the survey with friends and relatives who have chronic health problems that impact on their daily life activities and encourage them to complete the questionnaire.
5. The English and French questionnaires were placed in ‘SurveyMonkey’ and went live on October 1, 2016 and closed on January 8, 2017. The response rate was monitored by condition and additional follow-ups were undertaken with the national organizations, provincial/territorial affiliates of those organizations and support groups.
6. There were 20 health conditions on the original list compiled by the research team. Our goal was to have a minimum of 40 respondents for each of the 20 episodic health conditions. This goal was achieved for 13 of the conditions.

Findings

7. The majority of respondents (76%) reported having more than one health condition.
8. Most respondents (745 or 78%) reported that the impact of their health condition on their daily activities is unpredictable.
9. Respondents were asked if their ability to do their daily activities was getting better, getting worse or staying the same. Almost half (44%) said that their condition varied too much to choose one category.
10. 419 or 44% reported that they were completely unable to undertake one of the six life roles – worker, parent, spouse/partner, learner, volunteer or care giver – because of their episodic health condition(s).
11. Among active labour force participants, 77% said that their health condition(s) had an impact on their ability to participate in paid work or in a business.

12. While experiencing an illness episode, most respondents in the active labour force – both those with intermittent work capacity and those without – say “sometimes I can, sometimes I cannot” when asked if able to work during an illness episode.
13. 74% of respondents who were employed when they completed the survey questionnaire were in non-precarious (permanent) jobs – either full-time or part-time.
14. 80% of respondents who are employed in permanent (non-precarious) jobs have access to extended health care benefits dropping to 43% who are employed in precarious jobs and to 28% among those individuals who are seeking employment
15. Respondents who are in non-precarious jobs have the highest rate of disclosure of all of their health conditions to their present/ previous employer – 59% dropping to 51% among respondents in precarious jobs and below half (47%) among individuals who are actively seeking employment.
16. Among respondents who are employed in non-precarious jobs and who answered the questions on workplace accommodation, 26% reported that they needed no job accommodation and 4% did not answer the question. Among the remaining respondents, only 31% got everything that they asked for.
17. Among respondents who are employed in precarious jobs and who answered the questions on workplace accommodation, 32% reported that they needed no job accommodation and 9% did not answer the question. Among the remaining respondents, 32% got everything that they asked for.
18. Among respondents who answered the question on personal income, 15% had income of \$80,000 or more (before taxes and deductions) in the previous 12 months; by contrast, 36% had less than \$20,000.
19. Among respondents who answered the question on household income, 41% reported total household income of \$80,000 or more while 29% reported household income of under \$40,000. When asked if the household income met their basic needs, 31% said that it did not.
20. When asked, “what was the most challenging about living with a chronic health condition”, some responses were short and to the point including “very isolating condition”, “working through fatigue and pain”, “unpredictable”, “uncertainties”. Others provided a more detailed description of their life – in the past, as it is today and fear for the future including:
 - ✚ the **physical impact** of their pain and/or fatigue, the side effects of their medication, loss of mobility and finding a toilet;
 - ✚ the **unpredictability** resulting in being unable to plan or commit to anything, the uncertainty of what to expect thus making living a constant struggle and creating problems in the workplace;
 - ✚ the **work implications** of not being able to work, losing job/career, being under-employed/under paid, being demoted/having to change jobs, having to work when ill, lack of accommodation in the workplace (flex time, work from home), lack of sick days, job stagnation/no ability to advance, attitudinal barriers and unsupportive employers/co-workers;

- ✚ the **personal impact** including losing autonomy, dependence on others, loss of driver's license, experiencing stigma and discrimination;
- ✚ the **emotional impact** including anxiety, depression, frustration, stress, being overwhelmed, embarrassment, shame and thoughts of suicide;
- ✚ the **invisibility** of their condition(s) because others cannot see "it" and therefore do not believe or understand thus needing to constantly provide an explanation to others;
- ✚ their **quality of life** resulting in loss of activities that brought joy (gardening, travel, sports), "being able to do what I want to do" and having the energy only to work (work/life balance);
- ✚ **being poor** and not being able to find affordable housing, the financial strain of trying to make ends meet and of always having to make choices between basics;
- ✚ **navigating the system** including social assistance rules, CPP-D, long waiting lists, having to self-advocate;
- ✚ the impact on **relationships** including their children, their spouse/partner, relatives and friends; and
- ✚ the **additional expenses** for such items as prescriptions, treatments and special foods.

21. When asked, "what do you think could be done to improve your quality of life?", some respondents provided some concrete suggestions including:

- ✚ **improved experience in the workplace** through increased awareness by employers of episodic health conditions, workplace accommodations such as flexible work hours, more sick days, help in finding suitable work;
- ✚ **more disability supports** including stress reduction programs, supports for family/spouse, increased supports generally, improvement in existing support programs;
- ✚ **changes to the health care system** through easier access to health care professionals including specialists, more training of health care professional concerning people with multiple and complex medical conditions, increased health benefits, better funding for mental health supports, better medications, expansion of assisted death legislation;
- ✚ **improvements to the existing "disability support system"** by increasing awareness of episodic disability, more understanding by insurance companies of episodic disabilities, more research concerning particular health conditions, more public washrooms, more accessible public spaces;
- ✚ **providing adequate income support** by increasing welfare payments, have a guaranteed basic income, financial security, increased benefit rates; and
- ✚ **offering assistance with expenses** including affordable access to exercise programs, the cost of medications and treatments, the cost of schooling and retraining, the cost of transportation.

22. When asked for any additional comments about the experience of living with an episodic health condition, respondents mirrored what had been said in their response to the previous question emphasizing:

- ✦ changes in the **workplace** through increased awareness of what an episodic or invisible health condition is, removing attitudinal barriers, reducing stress in the workplace, more sick days, improving workplace accommodation to include flex time and ability to work from home, help finding employment and support with retraining;
- ✦ changes to the **health care and sickness support systems** through increased awareness of what an episodic health condition is among all officials associated with programs and services, improvement in health care coverage to include medications and treatments, increased funding for awareness training, increased funding for research, easier and faster access to health care specialists and improved coverage for short- and long-term disability;
- ✦ **increased awareness** in general society about what an episodic health condition is; and
- ✦ changes to the **income support system** through increased welfare payments to realistically cover living expenses, removal of barriers to CPP-D concerning episodic health conditions, creation of a guaranteed income and financial security.

Conclusions and next steps

23. The results from this new survey provide further insights into the impact of living with an episodic health condition. In summary, the main issues include:

- ✦ **increased awareness** of what it means to live with an episodic health condition.
- ✦ **increased income support** through provision of a basic income, expansion of CPP-D coverage to include episodic health conditions, more affordable housing, more affordable transportation, more affordable exercise programs.
- ✦ **improved health coverage** including better access to medications and treatments including medical marijuana, increased funding for mental health supports, better access to support groups, easier and faster access to specialists or treatments.
- ✦ **improved conditions in the labour market** including availability of health care benefits for persons in precarious jobs, increased supports in obtaining training and re-training, increased awareness of the accommodations required to support the hiring and retention of persons with episodic health conditions.
- ✦ **improved conditions in the workplace** including improved leave policies to accommodate intermittent work capacity, increased awareness of the nature and extent of “soft” accommodations required to support persons with episodic health conditions, development of guidelines concerning disclosure.

The findings outlined in this report advance the emerging literature on episodic disability and employment summarized in Section 5.4. Building on the seminal work of Antae *et al.* (2013), Lysaght *et al.* (2011), Smith Fowler *et al.* (2011) and Vick (2012, 2014), this survey provides further insights into the issue of precarious/non-precarious employment, disclosure of health conditions to employers, and attitudes of co-workers.

1. Introduction

Almost 1,000 Canadians who are living with an episodic health condition have *spoken out* about the impact that their health condition has on their life choices and their lives. This glimpse, captured in the word cloud on the cover of this report, provides us with some insights into their experiences in the workplace and other aspects of their life. This report provides details on these issues.

Members of the research team and the organizations representing various episodic health conditions reached out to Canadians through social media to apprise them of the survey and to encourage their participation. The questionnaire and supporting materials were provided in both official languages.

Of the 953 respondents who completed the questions on their health conditions and employment status:

- 43.2% live in Ontario;
- 89.1% completed the questionnaire in English;
- 76.3% are women;
- 71.4% are aged 25 to 54 years;
- 81.1% have some post-secondary education; and
- 59.3% are employed and 6.1% are seeking employment.

Appendix B of this report includes further breakdowns on each of these characteristics.

The research team acknowledges that this sample is not representative of the population with episodic health conditions in Canada. However, it is our opinion that these respondents have provided a rich, contextualized understanding of what it means to live with an episodic health condition and its impact on their ability to be active labour force participants, its impact on their other life roles and its impact on their social and economic situation. Because the questionnaire was a hybrid of closed and open-ended questions, it afforded the opportunity to the respondent to provide an overview of her/his life experiences.

2. Background

Over the last decade, studies that focussed on episodic health conditions have emerged as a critical component of work disability policy research. There is a growing understanding that many people with specific health conditions experience a course of wellness and illness episodes that impact on their work capacity in unpredictable ways (Furrie, 2010). Lysaght *et al.*'s (2011) review on intermittent work capacity (IWC) focused on the challenges related to the worker (the person with an episodic disability), the employer and employment context, and the larger social environment. They found that the impact of episodic disability on work capacity and employment was influenced by a multitude of factors that varied across individuals and circumstances including:

- the clinical course of the condition;
- the individual and her/his ability to manage the condition;
- the nature of the work and characteristics of the workplace, including the capacity to implement appropriate accommodations;
- employers' attitudes towards disability; and
- the larger labour market and economic conditions.

Smith-Fowler's review (2011) explored how episodic disability has been defined in the literature, the extent and nature of labour force attachment by people with IWC, systemic and structural factors that impact the experience of employment of people with disabilities who have IWC, and innovative and promising practices.

These reviews noted that although much is known about episodic disability and employment, the term episodic disability was only beginning to find its way into the literature. More recently, Furrie (2013) explored definitions of episodic disability in the context of employment, and highlighted the many ways it has been defined, as well as the similarities and differences across definitions. Common across definitions are notions of reoccurring and unpredictable changes in health status that impact employment.

This report documents the first findings from a survey of Canadians who have an episodic health condition and adds to this growing knowledge base. It is one component of a larger research project titled "Learning from Each Other". This three-phase project has, as its focus, improving our understanding of the employment needs of people with episodic disabilities. This may result in service enhancements, such as enhancing JAS' (CCRW's Job Accommodation Service) response to people experiencing episodic disability. This service has evolved over its 15 years to keep stride with the changing economic environment, the rapid development of aids and devices to support all people with disabilities, legislation concerning the duty to accommodate and the increased awareness of employers of the advantages to hire and retain employees with disabilities. Enhancing support to workers with episodic disabilities would be the next step in its evolution.

The three phases of the project include Information Gathering (Phase 1), Enhancement of JAS[®] and the Development of Materials (Phase 2) and Dissemination to Effect Change (Phase 3).

- Phase 1 includes five activities
 - a [statistical profile](#) of people with episodic disabilities derived from the 2012 Canadian Survey on Disability including a literature review,
 - the development of a questionnaire to be completed by individuals who have health conditions that result in unpredictable episodes of illness and wellness,
 - a survey of individuals with episodic disabilities and the dissemination of the findings,
 - an environmental scan of employers' policies and programs to accommodate employees with fluctuating health status, and
 - a review of JAS[®] to determine its' current capacity with respect to accommodating the needs of people with episodic disabilities.
- Phase 2 (Development of Resource Materials) involves the development of the resource materials.
- Phase 3 (Dissemination to Effect Change) includes the development of a media plan, webinars for employers, service providers and people with episodic disabilities and their supports, and the development and conduct of an evaluation survey to measure the impact that the resource materials have had to effect change.

Partial funding for Phase 1 was obtained through a Seed Grant from the Centre for Research on Work Disability Policy that generated two outputs. The first was a statistical profile of adults with disabilities based on data from the 2012 Canadian Survey on Disability, informed by the review of academic and “grey” literature. The second was a questionnaire that addresses the impact of living with an episodic health condition, vetted by community-based organizations that represent the individuals with those health conditions.

Funding for the conduct of the survey and dissemination of the findings upon which this report is based was provided by the Office for Disability Issues (ODI), Employment and Social Development Canada. This report provides only an overview of the survey results and is the final deliverable for ODI. As such, it highlights a broad range of issues but has, as its focus, the impacts that having an episodic health conditions have within the employment milieu. The lived experience responses obtained through the three open-ended questions at the end of the survey informs the presentation of data derived from the close-ended questions. Wherever possible, respondents' own words are included to put a “face” to the numbers.

This report is only one in a series of reports, papers and fact sheets that will be produced using the data from this rich database.

3. Methodology

3.1 *How did we reach the respondents?*

Our initial strategy

The success of the project rested with the organizations and associations that represent the selected health conditions that were identified by the research team. (See Appendix B for the list of organizations and associations). We sought their support to inform their members about the research, to indicate their support of the initiative and to encourage those with lived experience to complete the questionnaire. In return for their support, the research team agreed to provide a condition-specific fact sheet to each organization. The research team provided each organization with a backgrounder and sample tweets to use in informing their stakeholders about the survey. (See Appendix C for a copy of the backgrounder and sample tweets.)

Members of the research team also used their networks and social media to increase the response rate.

Because not all Canadians with a health condition are members of an organization, respondents were asked to share the knowledge of the survey with friends and relatives who have chronic health problems that impact on their daily life activities and encourage them to complete the questionnaire. This sharing of the knowledge is a recognized method in non-probability sampling known as the “snowball sample” that is appropriate to use in research when the members of a population are difficult to locate. Snowball sampling does not lead to a representative sample, but the research team decided that it was an appropriate methodology for this qualitative survey.

We aimed for a minimum of 40 respondents per health condition. Based on previous experience, we believed that this sample size would be sufficient to capture a range of diverse experiences as input to the next phase of our research. Assuming all identified organizations agree to participate, the total number of respondents was anticipated to be between 800 and 1,000.

The questionnaire was developed by the research team and organizations provided input to the first draft. The questionnaire was tested in English by two organizations. The questionnaire was translated and the French questionnaire was tested by one organization. A copy of the questionnaire (in English and French) is included as Appendix D.

The English and French questionnaires were placed in ‘SurveyMonkey’ and went live on October 1, 2016 and closed on January 8, 2017.

Our follow-up to increase response rates

We monitored the response rate by condition and did additional follow-ups with the national organizations. We also did an Internet scan and sent out the survey information to provincial/territorial affiliates and support groups.

3.2 Who answered the questionnaire? What episodic health conditions did they report? How did they respond to the open-ended questions to provide a summary of their lived experience?

Table 1. Respondents by episodic health condition		
Disease/disorder	Number of respondents	% of total respondents
Total Respondents	953	100.0%
Anxiety	415	43.5%
Depression	339	35.6%
Chronic pain	250	26.2%
Arthritis	241	25.3%
Migraines	162	17.0%
Crohn's disease and Ulcerative Colitis	157	16.5%
Multiple Sclerosis	120	12.6%
Asthma	116	12.2%
Post-traumatic stress disorder	116	12.2%
Diabetes	81	8.5%
Bi-polar disorder	59	6.2%
Epilepsy	53	5.6%
HIV/AIDS	51	5.4%
<i>Fatigue</i>	48	5.0%
<i>Fibromyalgia</i>	47	4.9%
Lupus	37	3.9%
Cancer	27	2.8%
Chronic obstructive pulmonary disease (including chronic bronchitis and emphysema)	20	2.1%
Substance abuse disorder	17	1.8%
Parkinson's Disease	10	1.0%
Meniere's Disease	6	0.6%
Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)	5	0.5%
Hepatitis C	5	0.5%
Other conditions (non-mental)	305	32.0%
Other mental disorders	55	5.8%

Who answered the questionnaire?

There were 1,275 Canadians who accessed the SurveyMonkey website (1,145 in English, 130 in French). Of those, 953 completed the questions on health conditions and employment status – the two criteria required for completion status.

There were 20 health conditions on the original list compiled by the research team (identified with blue shading in Table 1). The Mental Health Commission of Canada requested that we add substance abuse disorder. During the testing phase, respondents during the testing phase suggested that we add an “other” category.

What episodic health conditions did they report?

Our goal was to have 40 respondents for each of the 20 episodic health conditions. This goal was achieved for 13 of the conditions.

Almost half of the respondents (42%) indicated that they had “other” diseases or health conditions in addition to the 20 conditions listed. These write-in conditions were tabulated and among them, fibromyalgia and fatigue were the only two conditions that were identified by 40 or more respondents. The remaining “other” conditions were then coded into two broad categories – mental health related and non-mental health related.

The majority of respondents (76%) reported having more than one health condition. Among the 226 respondents who reported having only one health condition, 60 (27%) reported only having multiple sclerosis, 36 (16%) reported only having Crohn’s disease or ulcerative colitis, and 24 (11%) reported only having arthritis.

How did they respond to the open-ended questions to provide a summary of their lived experience?

Respondents were asked to tell us, in their own words, (1) what did they find the most challenging about living with their chronic health conditions, (2) what did they think could be done to improve their quality of life, and (3) anything else that they wanted to share about living with their health conditions. The response was overwhelming! There were 777 respondents who answered about their challenges, 707 who told us about what could be done to improve their quality of life and 448 who provided additional insights.

These responses were first reviewed independently by three associates of Adele Furrie Consulting Inc. (AFCI) including a social work professor from Carleton University with significant experience in qualitative research, AFCI’s in-house researcher and Adele Furrie. Each person created a typology within which to summarize the responses. Based on the consensus-based typology, these same three individuals summarized the responses using the typology, results were compared and consensus was achieved.

4. Literature review

Episodic disability has broad implications and impacts all areas of life. This report focuses on one key area, employment. Drawing on the existing literature, chronic health conditions that result in episodic disability may lead to intermittent work capacity and strained workplace relationships through stigma and disbelief. Episodic disability may also result in income insecurity. Precarious employment and disclosure at work may have key implications for the experiences of people living with chronic health conditions that produce episodic disability.

Intermittent work capacity

Episodic disabilities may fluctuate from day to day and even from hour to hour (Vick, 2014). This fluctuation varies in severity, length and predictability from one person to another (CWGHR, 2011) and thereby impacts daily work capacity in unpredictable ways (Furrie, 2010). The fluctuating impairments conflict with existing conceptions of disability and illness in public policy and in workplaces (Vick, 2012); that is, that disability is stable and permanent and that, when employees are ill, they will recover. Nor do employees with episodic disabilities fit into existing conceptions of the expected worker: someone who is healthy all of the time and consistently able to perform their job tasks (Stone et al., 2013).

Work capacity is influenced by a multitude of factors that vary across individuals and their circumstances. These include individual factors, such as the clinical course of the episodic condition and the person's ability to manage it (Lysaght et al., 2011), as well as workplace factors such as the nature of the person's job, employer attitudes towards disability and capacity to implement appropriate accommodations (Lysaght et al., 2011). System-wide factors also influence work capacity, such as the labour market and economic conditions (Lysaght et al., 2011).

Accommodating intermittent work capacity can be challenging, because accommodations may need to fluctuate and evolve over time in order to build predictability within the unpredictable by anticipating needs and establishing contingency plans (Lysaght et al., 2011). The most common need is flexibility, which involves arrangements such as work at home and flexible start and end times. These accommodations may impact the rest of the work team and are arrangements that co-workers themselves may also desire. Flexible arrangements may thus give rise to resentment among co-workers (Dunstan & MacEachen, 2014) and, as a result, employers may be reluctant to allow them.

Stigma and disbelief among employers and co-workers

The impairments that affect work capacity from many episodic conditions (for example, pain and fatigue) not only fluctuate, but they are invisible (Beatty & Kirby, 2006). In addition, these impairments may also be experienced by everyone at some time, although not severely enough to impact work capacity. Some episodic conditions are seen as less medically legitimate than others (Moss & Teghtsoonian, 2008; Toye et al., 2015). In addition, employees with episodic conditions may be stereotyped as unreliable and unproductive (Vick, 2014). Because of their

invisibility, fluctuation, and contested legitimacy, episodic disabilities can obscure understanding by supervisors and co-workers, inviting disbelief and suspicion of malingering (Vick, 2012). This disbelief and suspicion may strain workplace relationships when the reasons for decreased work capacity, being off work, and needing accommodations are not immediately visible or are highly stigmatized (Gewurtz & Kirsh, 2009).

The potential for disbelief, suspicion and discrimination may lead employees with episodic conditions to fear disclosing their impairments at work or their need for accommodations (Stergiou-Kita et al., 2016). Almost half of Canadians who need workplace accommodations do not request them (Till et al., 2015). Even when disabled workers ask for modified duties, a third do not receive this accommodation (Stone et al., 2014a). The most frequently cited reasons for not disclosing were feeling uncomfortable and fearing negative outcomes (Till et al., 2015).

Income insecurity and access to benefits

Disability income programs for Canadians comprise a variety of poorly integrated private and public plans (Meredith & Chia, 2015). Coverage by private insurance is highest among large employers and unionized workplaces (Meredith & Chia, 2015) and far lower for the precariously employed. For example, although two-thirds of full-time workers are covered by private insurance, only a quarter of part-time workers are (Meredith & Chia, 2015).

Many disability income-support programs regard people as either fully disabled or able to work (Stapleton & Tweddle, 2008). Some people with episodic disabilities who are able to work part-time or when they are well remain on full-time disability benefits (Stapleton & Tweddle, 2008), because they may otherwise lose coverage of extended healthcare costs. This is but one disincentive from returning to the workforce (CWGHR, 2011). However, some disability programs allow recipients to earn a limited income (Stapleton & Procyk, 2010). Those not on benefits often fear being disqualified in the future (Antao et al., 2013). Such circumstances threaten income security and stability, and can prevent people who experience intermittent work capacity from pursuing employment despite a desire to work.

There is a need for an income security system that could provide greater flexibility for people with episodic impairments. Instead of following existing eligibility requirements, disability income replacements could be restructured to allow for job trials and increased flexibility to move on and off benefits as needs fluctuate over time (Antao et al., 2013; Smith Fowler, 2011). These programs would need to be coordinated to provide a living income from disability benefits, employment, or both (Mental Health Commission, 2013). One accommodation that may allow people with intermittent work capacity to remain employed is part-time work (Palstam et al., 2013). However many employees, especially sole or primary breadwinners, cannot afford to work only part-time (Oldfield, 2015) and would need disability income replacement to supplement their employment income.

Some European governments offer partial disability benefits. For example, for sick-listed workers, Swedish social insurance provides 25, 50, and 75% benefits for those who are assessed

as being able to work 75, 50 and 25% of the time (Palstam et al., 2013). In Denmark, only a 50% reduction in work capacity is required to qualify for federal disability benefits (OECD, 2010). In Canada, permanent partial/part-time disability benefits are offered as add-ons under some private insurance plans (Stone et al., 2013; Cameron & Chouinard, 2014), but are associated with higher premiums.

Precarious employment

In recent decades, precarious employment (part-time, casual, contract, temporary, self-employment, or non-unionized work) has increased (Tompa et al., 2006). For example, in a study in southern Ontario reported that half of workers were employed in precarious work and 40% had no benefits beyond a basic wage (Lewchuck et al., 2014). Although precarious employment might provide the flexibility that is often needed by people with episodic disabilities, drawbacks include lower pay, job insecurity as well as a lack of employee benefits, access to training, union membership, and labour law protection (Facey & Eakin, 2010). Canadians with impairments are more likely to be in precarious employment than other Canadians (Wilton, 2006). In precarious employment, it is hard to build the supportive workplace relationships necessary to negotiate accommodations and to successfully implement them (Gates & Akabas, 2011). Finally, precarious employment and work insecurity may result in added stress, which may in turn exacerbate existing conditions (Vick & Lightman, 2010).

Not only is precarious employment a growing concern but, increasingly, employees with chronic illnesses compete with healthy colleagues to keep their jobs in shrinking labour markets (Stone et al., 2014b). Disclosing anything that harms their competitiveness may be risky.

Disclosure

As noted above, the invisibility, fluctuation, and contested legitimacy of some episodic disabilities can invite disbelief. However, if employees or job applicants need accommodations, they are faced with revealing their need (Toth & Dewa, 2014). In addition, there are many occasions when employees may need to explain why they need help or time off, or cannot do a task (Oldfield, et al., 2015). Disclosure and its consequences, which can be positive, negative, or anywhere in between, are influenced by the quality of workplace relationships (Oldfield et al., 2015), the climate of the workplace (von Schrader et al., 2014), and organizational culture (Kirsh & Gewurtz, 2011).

There are many options for disclosure. Employees with episodic disabilities may disclose their condition, only their impairments, or only their need for accommodation (McDonald-Wilson et al., 2011). They may tell only people they trust at work, and may tailor the timing of their disclosure (McDonald-Wilson et al., 2011) to minimize risk or maximize understanding. They may say that their impairments come from something other than the condition, if that is more likely to be believed (Oldfield et al., 2015).

Potential benefits of disclosure include gaining emotional and instrumental support from co-workers or supervisors who have also experienced disability and understanding from those

who have not (Oldfield et al., 2016). People with episodic conditions may tell a supervisor first, to improve communication with other stakeholders (Oldfield et al., 2016), which is a helpful strategy for meeting ongoing needs (Yarker et al., 2010). Disclosure may prevent misunderstandings about one's absences or ill health and forestall rumors. However, before disclosing, it is important to consider the quality of workplace relationships, work climate and organizational culture (Oldfield et al., 2016). Finally, disclosing a need for accommodations to a supervisor or employer is the first step in negotiating them.

Potential pitfalls of disclosing invisible, fluctuating impairments include disbelief that the person disclosing has a legitimate disability. Workmates may assume that employees with episodic conditions are less competent (Brohan et al., 2012), unreliable (Munir et al., 2005), burden their colleagues (Lysaght & Krupa, 2014), and lower team productivity. Workmates may downplay the condition's seriousness (Toth & Dewa, 2014), assuming that the employee is lazy (Kristman et al., 2014). After disclosing episodic disability, employees may receive unwanted pity, and their behaviour may be interpreted as related to the disability when it is not (Stone et al., 2013). They may also be blamed for causing or exacerbating their illnesses (Vickers, 2012). Disclosure may result in discrimination, which is being treated unfairly because of difference. Employees with episodic disabilities may be monitored more closely than others (MacDonald-Wilson et al., 2011) and harassed (von Schrader et al., 2014). Finally, these employees may lose their jobs through layoff or contract non-renewal (Beatty, 2006), thereby hiding discrimination. The degree of stigma associated with the episodic condition may magnify any of these disclosure risks.

Conclusion

Given that episodic conditions may result in intermittent work capacity, strained workplace relationships, income insecurity, and disclosure dilemmas, we need to understand the experiences of people with episodic disability in the context of the workplace – finding work, keeping work, and advancing in the workplace.

5. Analysis

Summary

- There were 1,275 Canadians who accessed the SurveyMonkey website (1,145 in English, 130 in French). Of those, 953 completed at least the questions on health conditions and employment status – the two criteria required for inclusion in the research.
- Most respondents (745 or 78%) reported that the impact of their health condition on their daily activities is unpredictable.
- Respondents were asked if their ability to do their daily activities was getting better, getting worse or staying the same. Almost half (44%) said that their condition varied too much to choose one category.
- 419 or 44% reported that they were completely unable to undertake one of the six life roles – worker, parent, spouse/partner, learner, volunteer or care giver – because of their episodic health condition(s).
- Among active labour force participants, 77% said that their health condition(s) had an impact on their ability to participate in paid work or in a business.
- One in ten respondents (10.5%) of the 953 respondents reported that they were not a parent because of their episodic health condition(s).
- Slightly more than one in 10 (11.2%) of the 953 respondents said that they did not have a significant other because of their episodic health condition(s).
- Six out of 10 of the respondents (573 or 60.1%) reported that they were not considering school or training. Within that group, 121 reported that this was because of their episodic health conditions.
- Almost two out of ten respondents (19%) reported that they did not volunteer or participate in community activities because of their episodic health condition(s).
- Almost one out of ten respondents (9.2%) reported that they did not provide care to others because of their episodic health condition(s).
- Of the 953 respondents, 622 are employed, 78 are seeking employment and the remainder (253) are not in the labour force.
- While experiencing an illness episode, most respondents in the active labour force – both those with intermittent work capacity and those without – say “sometimes I can, sometimes I cannot” when asked if able to work.
- 458 of the 622 respondents who were employed when they completed the survey questionnaire were in non-precarious (permanent) jobs – either full-time or part-time. The remaining 164 respondents were in precarious jobs.
- The majority (80%) of the 458 respondents who are employed in permanent (non-precarious) jobs have access to extended health care benefits. The picture is very different for the respondents who are working but in precarious positions – only 43% have access to extended health care benefits and even worse for those individuals who are seeking employment – only 28% have access to extended health care benefits.

- Among respondents employed in permanent (non-precarious) jobs, 66% said the current job gives them the opportunity to use all of their education, training and skills and among respondents in precarious employment, the percentage was similar – 64%. The reverse was true for respondents who were seeking employment; only 33% reported that their last job allowed them to use all of their education, training and skills.
- With respect to disclosure, there are differences among the three populations within the active labour force population. Respondents who are in non-precarious jobs have the highest rate of disclosure of all of their health conditions to their present/ previous employer – 59% dropping to 51% among respondents in precarious jobs and below half (47%) among individuals who are actively seeking employment.
- Respondents were asked if their co-workers are/were aware of their episodic health condition(s). Among the 447 respondents who answered the question and who had a non-precarious job, only 7% reported that their co-workers are unaware of their health conditions. This percentage doubled to 14% among the 151 respondents who had precarious jobs and among the 71 respondents who are actively seeking employment.
- Of the 447 respondents who are employed in non-precarious jobs and who answered the questions on workplace accommodation, 26% reported that they needed no job accommodation and 4% did not answer the question. Among the remaining 313 respondents,
 - 31% got everything that they asked for;
 - 33% got some of what they asked for;
 - 26% needed accommodation but did not ask their employer; and
 - 10% asked but did not get the accommodation.
- Of the 164 respondents who are employed in precarious jobs and who answered the questions on workplace accommodation, 32% reported that they needed no job accommodation and 9% did not answer the question. Among the remaining 100 respondents,
 - 32% got everything that they asked for;
 - 31% got some of what they asked for;
 - 26% needed accommodation but did not ask their employer; and
 - 11% asked but did not get the accommodation.
- Of the 953 respondents, 794 answered the question on personal income. Among those who responded, 15% had income of \$80,000 or more (before taxes and deductions) in the previous 12 months. By contrast, 36% had less than \$20,000.
- Of the 953 respondents, 736 provided total income data. Among those who did report, 41% reported total household income of \$80,000 or more while 29% reported household income of under \$40,000.
- When asked if the household income met their basic needs, 31% said that it did not.

5.1 *What are the characteristics of the episodic health condition?*

The survey explored two characteristics of episodic health conditions – predictability and stability. While there was some consistency across all respondents, there were some notable differences across the health conditions on both characteristics.

Predictability:

Most respondents (745 or 78%) reported that the impact of their health condition on their daily activities is unpredictable. This was lower among respondents who reported multiple sclerosis (70.6%) and those reporting diabetes (72.5%). By contrast, individuals reporting migraines or fibromyalgia were more likely than average to report unpredictability – 87.1% and 89.1% respectively. This unpredictability wreaked havoc for many in all aspects of their lives. As depicted in the following quotes, unpredictability and uncertainty associated with episodic health conditions makes planning almost impossible. As well, respondents indicated that because their conditions are invisible, others may not believe that they are ill, and that this exacerbates their situation.

“Unpredictability, trying to parent, missing out on social events, stigma, “faking” it on bad days, difficulty connecting with others at times (Female, 35-44 years, anxiety, depression, chronic pain, PTSD)

“The unpredictability: I don't consider myself as someone who is ill until I have a flare up but when they do occur, they can be quite severe. In the future, having a severe flare up while employed could pose as a challenge as some flare ups have lasted up to 6 months with substantial cognitive and physical impairments and would mean that I would have to be unemployed for close to half a year before being able to enter the workforce again.” (Female, 15-24 years, multiple sclerosis)

“Unpredictability of symptoms; feeling like I am letting my co-workers / students down because of fatigue; feeling frustrated because I want to do more with my job, and outside of work; disappointed because this is not the career direction I planned to stay in” (Female, 35-44 years, multiple sclerosis, fatigue)

“Unpredictability of the combined conditions hampers future planning and also reliability, leading me to feel as though others may feel that they cannot “count” on me; this line of thinking, of course, exacerbates the condition. Sense of isolation: as though I am the only one experiencing such symptoms and that I am “cut off from society.” (Female, 45-54 years, anxiety, depression)

“The uncertainty of day-to-day living. Will I be able to eat or do anything today. If I can for how long....” (Female, 55-64 years, arthritis, chronic pain, depression, multiple sclerosis)

“The unpredictability of the disease. And people not understanding that I'm ill because "I don't look sick".” (Female, aged 35-44 years, arthritis, Crohn’s disease)

Stability:

Respondents were asked if their ability to do their daily activities was getting better, getting worse or staying the same. **Almost half (44%) said that their condition varied too much to choose one category.** The inability to choose one category was more prominent among persons reporting fibromyalgia (65.2%), asthma (56.5%) or post-traumatic stress disorder (50.4%).

Almost one in five respondents (19.2%) reported that their condition was getting worse. This proportion was greater among people reporting arthritis (28.7%), chronic pain (28.7%), fatigue (26.7%), HIV/AIDS (27.5%) or multiple sclerosis (28.6%) but less among people reporting Crohn’s disease/ulcerative colitis (10.9%) or epilepsy (13.2%).

5.2 What is the impact on life roles?

Respondents were asked about the impact that their episodic health condition has on their various life roles. From the responses provided, one sees that the impact is far-reaching.

Of the 953 respondents, **419 or 44% reported that they were completely unable to undertake one of the six life roles – worker, parent, spouse/partner, learner, volunteer or care giver – because of their episodic health condition(s).** Almost half (46.8%) were unable to take on one role, 27.2% were unable to take on two roles and 26% were unable to take on three or more roles. Within these three groups, respondents with pain, anxiety, depression and arthritis were more likely to say they were completely unable to undertake one of the six life roles.

Each role was then examined in detail. Although there are differences in terms of the episodic conditions reported by respondents as affecting their participation in life roles, there are some commonalities. These are summarized in Table 2 below for those health conditions where 40 or more respondents reported that they did not undertake at least one life role. *(Recall that the majority of respondents reported more than one health condition.)*

- Over all, 50% of respondents reported that they did not work because of their health condition(s). This percentage was much higher among respondents who reported having multiple sclerosis (69%) and among those who reported chronic pain (59%), asthma (58%) and PTSD (57%); by contrast, the percentage of persons reporting Crohn’s disease/ulcerative colitis or migraines was lower at 39% and 44% respectively.
- 24% of respondents reported that they chose not to be a parent because of their health condition(s). Among persons reporting Crohn’s disease /ulcerative colitis, this percentage was much higher at 33%; by contrast, the percentage of persons reporting multiple sclerosis was lower at 12%.
- 26% of respondents reported that they were not in an intimate relationship because of their health condition(s). This was much higher for persons reporting PTSD (39%) and higher for

persons reporting anxiety (31%) and chronic pain (30%); by contrast, the percentage of persons reporting Crohn’s disease/ulcerative colitis or multiple sclerosis was lower at 16%.

- 29% of respondents indicated that they did not attend school or training because of their health conditions. For persons reporting PTSD, this was higher at 37% and among persons reporting chronic pain, 35%.
- 43% reported that they did not volunteer because of their health condition(s). This percentage was higher among persons reporting arthritis (50%), asthma (50%) and chronic pain (48%).
- 21% reported that they did not provide care to others because of their health conditions. This was much higher among persons reporting asthma (31%), arthritis (28%) and multiple sclerosis (25%).

Table 2. Respondents who reported that they did not undertake at least one life role, by life role and presence of episodic health condition										
	All conditions	Anxiety	Arthritis	Asthma	Chronic pain	Crohn's disease or Ulcerative colitis	Depression	Multiple sclerosis	Migraines	PTSD
Work	50%	50%	56%	58%	59%	39%	53%	69%	44%	57%
Parent	24%	24%	19%	19%	18%	33%	21%	12%	27%	18%
Spouse/partner	26%	31%	24%	19%	30%	16%	30%	16%	29%	39%
School/training	29%	31%	32%	23%	35%	24%	32%	29%	32%	37%
Volunteer	43%	42%	50%	50%	48%	44%	46%	39%	47%	43%
Caregiver	21%	16%	28%	31%	24%	16%	16%	25%	15%	21%
Total	419	191	123	52	152	75	160	51	78	67

To help understand the depth of the impact, we selected some of the comments made by respondents who reported some of these nine conditions.

Post-traumatic stress disorder (PTSD) was reported by 116 (12.2%) of respondents and 67 (16%) of respondents who did not undertake at least one life role. PTSD was reported by all ages and genders and the nature of the impact was expressed in a variety of ways.

“Never being able to relax and take care of myself because of work. I cannot afford to not work. So, I am in pain all of the time mentally and physically. It doesn't leave much for my family at the end of the day.” (Female, 25-34 years, anxiety, arthritis, bi-polar disorder, depression, epilepsy, PTSD)

“The unpredictability of flare ups; dealing with triggers in the workplace (i.e. meetings with men alone behind closed doors).” (Female, 35-44 years, anxiety, chronic pain, depression, PTSD)

“For my PTSD, I need to keep in check my aggressiveness, to reduce my hyper-awareness and loneliness feelings.....etc.” (No gender reported, no age reported, arthritis, PTSD)

Migraines was reported by 162 (17%) of respondents and 78 (19%) of respondents who did not undertake at least one life role. The majority of respondents who reported migraines did so along with other episodic health conditions. When asked “What do you consider to be the health condition that has the most impact on your daily activities?”, the majority reported migraines and then another condition.

“...with migraines, I find the fatigue most challenging after day 4 or 5 of having one. I am fortunate my medications work but the lingering effects are so tiring and make it hard to get up.” (Female, 35-44 years, migraines and anxiety)

“The migraines are very debilitating and I do not always know when I will get them which make it hard to plan. When they are very bad I cannot get out of bed to even work from home. Additionally, the anxiety and depression has led me to take a sick leave (unspecified as to my condition to my employer) for a week as well as numerous sick days off to deal with panic attacks or consistent crying.” (Female, 25-34 years, anxiety, arthritis, depression and migraines)

Crohn’s disease or ulcerative colitis was reported by 157 (16.5%) of respondents and 75 (18%) of respondents who did not undertake at least one life role. Most respondents reported both Crohn’s/ulcerative colitis along with at least one other episodic health condition. However, when asked what disease had the most impact on their daily activities, most reported that it was their Crohn’s or colitis.

“Not knowing when I’ll have a flare up; occasional intense pain; restaurants; stores, etc. not allowing the use of their bathrooms. Finding a toilet!!” (Female, 55-64 years, anxiety, and Crohn’s/colitis)

“Keeping the chronic exhaustion pain and funky tummy from interfering in my life, i.e. - late to work because of bathroom time. Too tired to be patient with students or spend quality time with family and friends. Arthritis pain interferes with dragon boating, walking etc.” (Female, 45-54 years, arthritis and Crohn’s/colitis)

“I have no quality of life. I have difficulty doing anything because of my health conditions. Wait times to see doctors are too long, especially specialists. Simple things like housework are a challenge. Even visiting with family is exhausting. Showering is exhausting. There isn't enough income for basic living. Some medications affect my memory and my ability to absorb information. Constant pain and excessive trips to the bathroom interfere with everything. No energy, and it's still hard as a former workaholic to accept that I can no longer do the things I want to do or need to do to improve our financial situation. I live in stress and fear of ending up homeless. My husband who is my caregiver is now sick with his own challenges. Wait times for government programs are too long and are not back dated/paid. Food from the food bank (although appreciated)

does not always agree with my disease.” (No gender reported, no age reported, depression and Crohn’s/colitis, arthritis, chronic pain, lower spine injury)

“I never know when there will be a flare up. My job requires me to be available on a phone for 8 hours a day which doesn't always work for me since a flare up can keep me in the restroom for a long time & suddenly. Despite taking meds, seeing specialist and eating right I still have flare ups & it makes it hard to be social, work, eat out. I don't like to be caught in crowds. Worry about having access to a bathroom.” (Female, 35-44 years, Crohn’s/colitis)

Chronic pain was reported by 250 (26.2%) of the respondents and 152 (36%) of respondents who did not undertake at least one life role. Only two respondents reported just chronic pain. Some respondents reported that it was pain that limited their activities while others reported the underlying condition that was the cause of the pain – multiple sclerosis, Crohn’s disease/ulcerative colitis or arthritis.

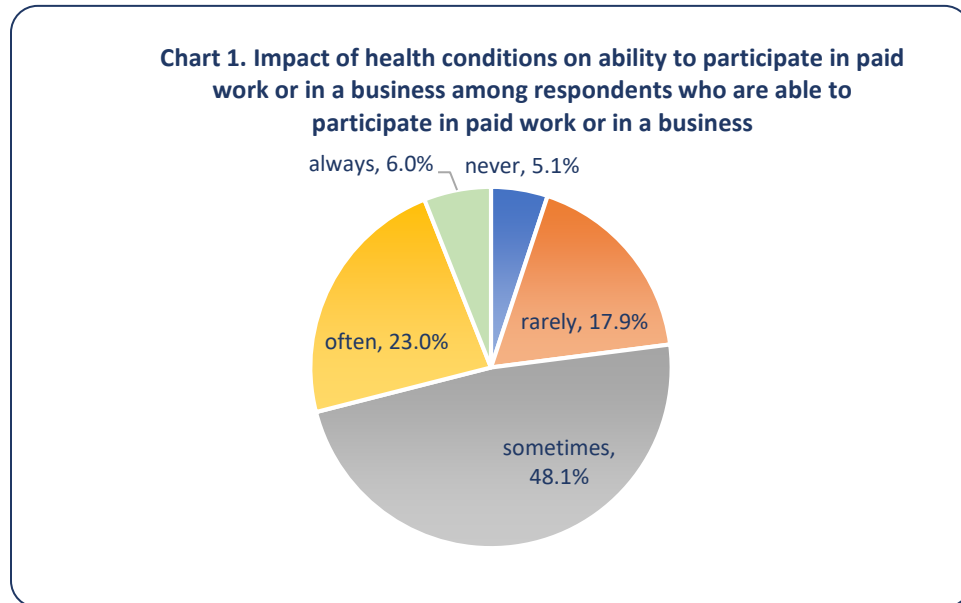
“I get extremely anxious when someone needs to confront me about any issues. I am taking mindfulness classes to deal with this. The pain I have often means I walk with a list or am unable to do stairs or pick up my grandson while I care for him. I sometimes get bad enough that I am unable to dress myself (socks and bra the most difficult) open jars or even soda bottles. Some days I can't join recreational things I have always enjoyed such as dancing, rock climbing, or even taking a long walk etc.” (Female, 55-64 years, arthritis, chronic pain, lupus and PTSD)

“My income meets my basic needs, but not the additional expenses caused by my disability. The extended health benefits I receive are appropriate for the average worker, but not someone with complex and ongoing health needs. Chronic pain and fatigue caused by my condition makes commuting a challenge, and means that I ought to work reduced hours. However, if I do that, I won't be able to afford rent.” (Female, 25-34 years, asthma, chronic pain, PTSD and neuromyelitis optica)

Impact on ability to participate in paid work or in a business

More than two out of ten (21.9%) of all respondents do not participate in paid work or in a business because of their episodic health condition(s). This percentage was more than double among persons reporting anxiety (45.9%). It was also much higher among respondents reporting chronic pain (43.1%), depression (40.6%) and arthritis (33%).

Another 2.9% do not participate for reasons other than their health condition(s) and less than one percent said that they preferred not to answer the question.



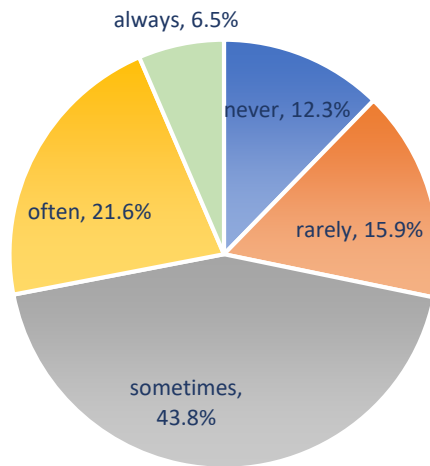
Of the remaining 712 respondents, 77% said that their health condition(s) had an impact on their ability to participate in paid work or in a business – sometimes (48.1%), often (23%) or always (6%). This combined percentage was much higher among respondents who

reported post-traumatic stress disorder (91%), bi-polar disorder (89.1%), depression (88.7%) and Crohn’s diseases or ulcerative colitis (88%).

Impact on role as a parent

One in ten respondents (10.5%) of the 953 respondents reported that they were not a parent because of their episodic health condition(s). Respondents in this group with one of these six episodic health conditions were much more likely to report that their health conditions were the reason why they were not a parent – anxiety (44.6%), depression (32.7%), chronic pain (27.7%), Crohn’s disease or ulcerative colitis (24.8%), arthritis (22.8%) and migraines (20.8).

Chart 2. Impact of health conditions on parenting role among respondents who are parents



Just over three in ten (35.6%) said they were not a parent for reasons other than their health condition(s) and 3.5% said they preferred not to answer the question. Of the remaining 464 respondents, 72% said that their health condition(s) had an impact on their parenting role – sometimes

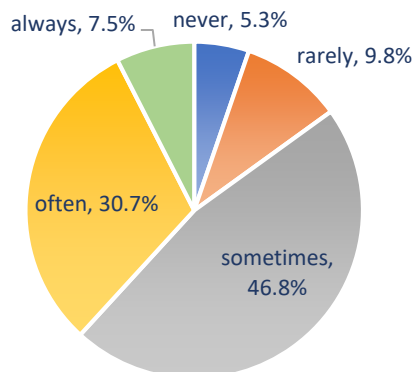
(43.8%), often (21.6%) or always (6.5%). This combined percentage was much higher among respondents who reported chronic pain (85.6%), Crohn’s diseases or ulcerative colitis (84.3%), post-traumatic stress disorder (82.4%) and migraines (80.5%).

Impact on role as a spouse/partner

Slightly more than one in 10 (11.2%) of the 953 respondents said that they did not have a significant other because of their episodic health condition(s). Respondents in this group with one of these six episodic health conditions were much more likely to report that their health condition(s) was/were the reason why they were not in a significant relationship – anxiety (56.1%), depression (44.9%), chronic pain (42%), arthritis (28%), post-traumatic stress disorder (24.3%) and migraines (20.8%).

An additional 16.2% said they were not in a relationship for reasons not related to their health conditions and 2.2% said that they preferred not to answer the question

Chart 3. Impact of health conditions on relationship with spouse/partner among respondents who are in a relationship with a significant other

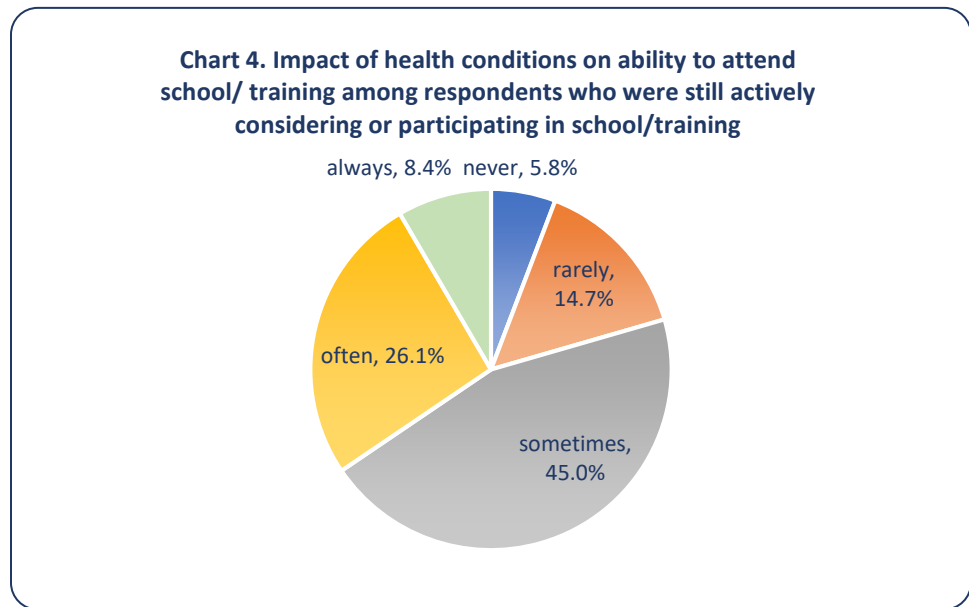


Of the remaining 665 respondents who were in a relationship, almost half (46.8%) reported that their health condition(s) “sometimes” impacted on their relationship, 30.7% reported that their

health condition(s) “often” impacted and 7.5% said it “always” had an impact. This proportion varied depending on the episodic health condition(s). Among those respondents who reported post-traumatic stress disorder, 95.6% reported that their health condition(s) had an impact “sometime”, “often” or “always” on their relationship with their spouse/partner; among those reporting chronic pain, 92.4%; depression, 92%; and migraines, 90.2%.

Impact on capacity to attend school/training

Six out of 10 of the respondents (573 or 60.1%) reported that they were not considering school or training. Within that group, 121 reported that this was because of their episodic health conditions. Respondents in this group with one of these six episodic health conditions were much more likely to report that their health condition(s) was/were the reason why they were not attending school or seeking training – anxiety (49.6%), chronic pain (43.8%), arthritis (32.2%), depression (32.1%), migraines (20.7%) and post-traumatic stress disorder (24.3%).



Among the remaining 380 respondents, 5.8% reported that their health conditions never impacted on their capacity to attend school or training and 14.7% reported that they were “rarely” limited. The remaining 79.5% experienced some decrease in their capacity because of

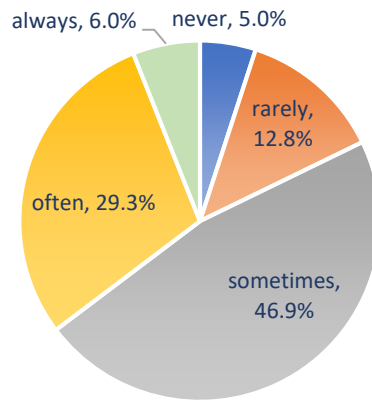
their episodic health condition(s). Among those respondents who reported Crohn’s disease or ulcerative colitis within these 380 respondents, the percentage was 87.9%; depression, 87%; arthritis, 86.6%; and migraines, 84.8%.

Impact on ability to volunteer or participate in community activities

Almost two out of ten respondents (19%) reported that they did not volunteer or participate in community activities because of their episodic health condition(s). Respondents in this group with one of these four episodic health conditions were much more likely to report that their health condition(s) was/were the reason why they did not volunteer or participate in community activities – anxiety (44.2%), chronic pain (40.4%), depression (40.3%) and arthritis (33.7%).

An additional 8.3% said they did not volunteer or participate in community activities for reasons not related to their health conditions and one percent said that they preferred not to answer the question

Chart 5. Impact of health conditions on ability to volunteer or participate in community activities among respondents who are volunteering or participating in community activities



Of the remaining 680 who did respond, 82.2% said that their health condition(s) had an impact on their ability to volunteer or participate in community activities. This combined percentage was higher among respondents who reported chronic pain (94.3%),

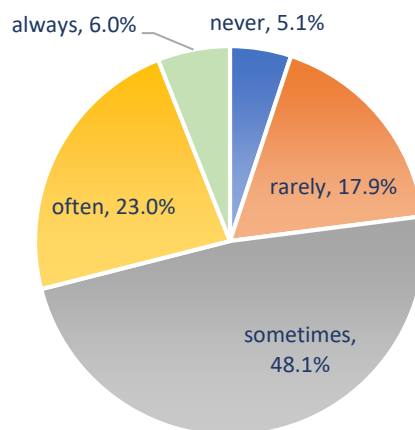
migraines (91%), depression (88.2%) and post-traumatic stress disorder (88%).

Impact on ability to provide care to others

Almost one out of ten respondents (9.2%) reported that they did not provide care to others because of their episodic health condition(s). Respondents in this group with one of these five episodic health conditions were much more likely to report that their health condition(s) was/were the reason why they did not provide care for others – chronic pain (42.1%), arthritis (39.8%), anxiety (35.2%), depression (29.6%) and asthma (18.1%).

An additional 10.5% said they did not provide care to others for reasons not related to their health conditions and 1.4% said that they preferred not to answer the question.

Chart 6. Impact of health conditions on ability to provide care to others among respondents who provide care to others



Of the remaining 749 who did respond, 77% said that their health condition(s) had an impact on their ability to care for others – sometimes (48.1%), often (23%) or always (6%). This

combined percentage was higher among respondents who reported fatigue (92.9%), chronic pain (88.5%), Crohn's disease or ulcerative colitis (85.6%) and post-traumatic stress disorder (84.3%).

What is the impact on leisure activities?

Respondents were asked about the impact that their episodic health condition(s) had on their ability to participate in leisure activities. Many spoke to the fact that it took all their energy to do the things they had to do – work, eat, clean their home, etc. Many spoke to the frustration of not being able to participate in the leisure activities that they used to do.

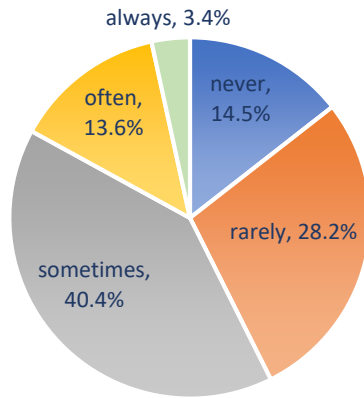
“Finding a balance in my leisure time; it seems that all I can do is work and this takes all my energy. I have no energy left to take care of myself.” (Female, 35-44 years, anxiety, chronic pain, PTSD)

“I find exercise is helpful to get me going but it depends on my level of energy and I am often fatigued.” (Male, 15-24 years, bipolar disorder)

“..... Being unable to do activities I used to so. Feeling my future is always going to be uncertain. Not being able to be the parent my kids deserve.” (Female, 35-44 years, multiple sclerosis)

Impact on passive leisure activities

Chart 7. Impact of health conditions on ability to participate in passive leisure activities among people who do participate in passive leisure activities

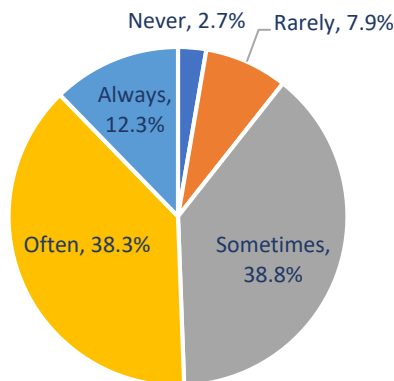


Of the 953 respondents, almost all (934) indicated that they did participate in passive leisure activities such as reading and watching TV. Almost six out of ten (57.3%) reported that their health condition(s) impacted on their passive leisure activities –

sometimes (40.4%), often (13.6%) and always (3.4%). This combined percentage was higher among respondents who reported fibromyalgia (76.6%), migraines (74.5%), post-traumatic stress disorder (72.6%), fatigue (70.8%) and chronic pain (70%).

Impact on physical leisure activities including exercise

Chart 8. Impact of health conditions on ability to participate in physical activities/exercise among people who do participate in physical activities/exercise



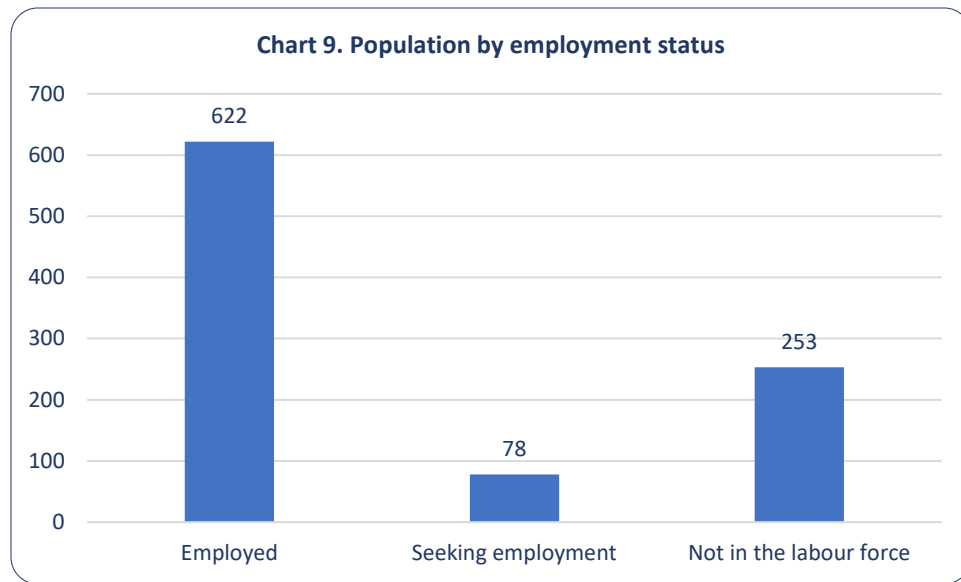
There were 80 respondents (8.4%) who reported that they did not participate in any physical leisure activities because of their health condition(s) 1.8% who did not participate for reasons other than their health condition(s) or who did not answer the

question. Among the remaining 856 who said that they did, of those, the majority (89.4%) said that the impact was sometimes (38.8%), often (38.3%) and always (12.3%). The combined percentage was higher among respondents who reported fibromyalgia (100.0%), chronic pain (95.2%), fatigue (95.1%) and migraines (94%).

What is the impact in the workplace of having an episodic health condition?

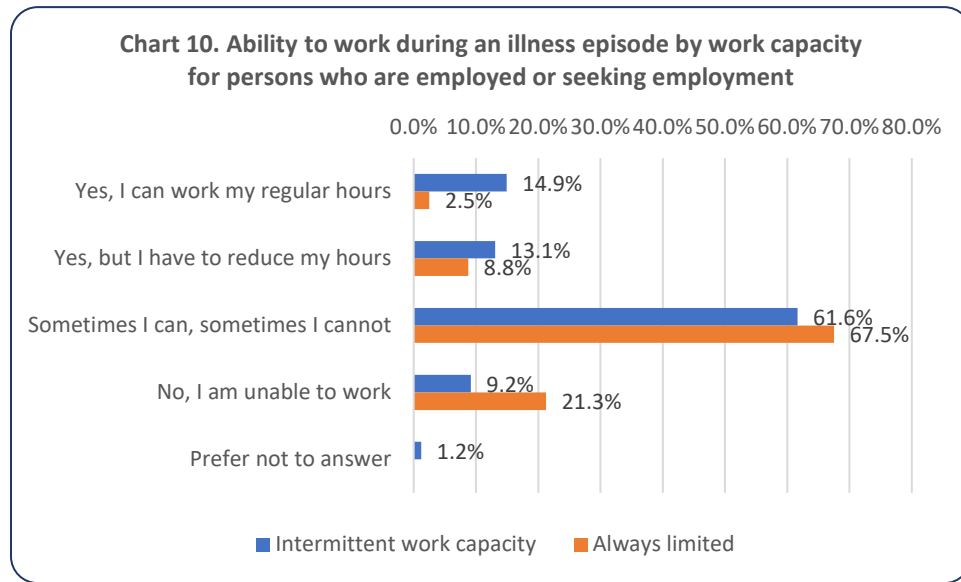
The focus of our research is the impact that having an episodic health condition has on one’s ability to secure and retain stable employment.

To establish our research population within the 953 respondents, we used the impact on work question which we discussed earlier in this report and applied the criteria that we had established in our analysis of the 2012 Canadian Survey on Disability data. We used this question to operationalize the concept of “intermittent work capacity”. We considered a respondent to have intermittent work capacity (IWC) if they responded “rarely”, “sometimes” or “often” to being affected in their ability to participate in paid work or in a business. All other respondents (those who answered “never” or “always” were considered not to have IWC. Against this variable, we categorized respondents as being part of the active labour force (either employed or seeking employment) and not in the labour force (retired, not actively seeking employment, completely prevented from working and non-response).



Of the 953 respondents, 622 are employed, 78 are seeking employment and the remainder (253) are not in the labour force. For the remainder of this sub-section of the report, the tables, charts and discussion with focus on the 700 respondents who

are active labour force participants – either employed or seeking employment.

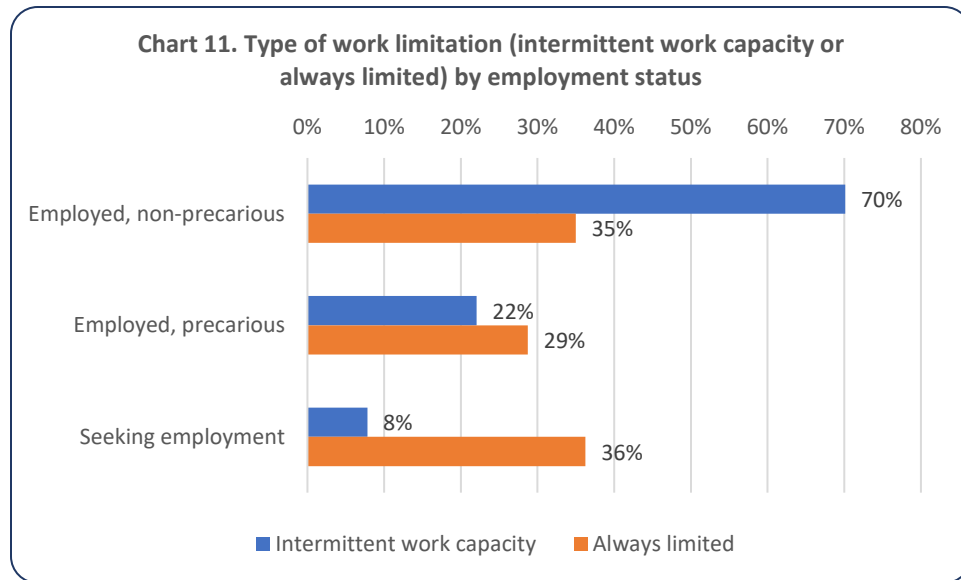


Within the 700 respondents who were working or seeking employment, 669 indicated that they had intermittent work capacity (rarely, sometimes or often limited at work) or they were always limited at work. The remaining 31 respondents either

reported that they were never limited or did not answer the work limitation question.

For both the intermittent work capacity and always limited populations, the majority report that sometimes they can work, sometimes they cannot. One sees differences between those respondents who have intermittent work capacity and those who are always limited at work. Only 2.5% of persons who are always limited at work report that they can work their regular hours during an illness episode compared to 14.9% of respondents who have intermittent work capacity. There is little difference between respondents who are employed and those who are seeking employment.

“Sometimes I can, sometimes I cannot” – this unpredictability makes it a challenge for both the respondent and her/his employer. For many respondents, this “makes life a struggle” and the “uncertainty of when an episode will occur” causes both stress and anxiety.

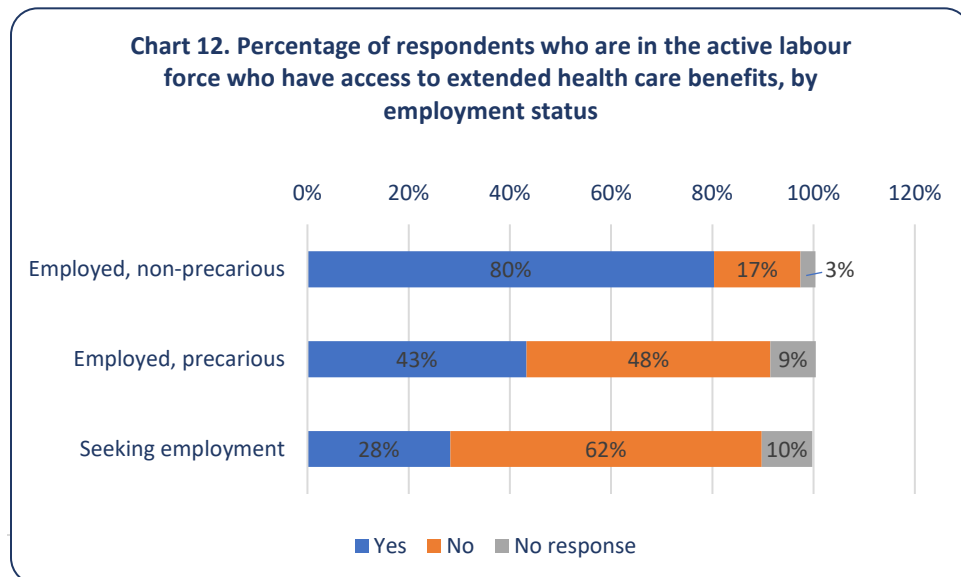


Another lens to use when looking at potential stressors is to explore the stability of the job. Respondents provided details about the nature of their employment and we used these data to dichotomize the employed population by the precarity of their employment. To do

this, we applied Tompa’s definition (Tompa, 2006) and determined that 458 of the 622 respondents who were employed when they completed the survey questionnaire were in non-precarious (permanent) jobs – either full-time or part-time. The remaining 164 respondents were in precarious jobs. The majority (70%) of respondents who had intermittent work capacity were employed in non-precarious jobs. There were 22% employed in precarious jobs and 8% were seeking employment. This distribution is far different from those respondents who were always limited. Here, only 35% were in non-precarious jobs, 29% were employed in precarious jobs and 36% were seeking employment.

Precarity is the focus of the remainder of this section because of growing concern related to non-permanent work arrangements (Lewchuk, 2014) and the associated lack of income security and access to health benefits.

Impact – Access to extended health care benefits



The majority of the 458 respondents who are employed in permanent (non-precarious) jobs have access to extended health care benefits. The picture is very different for the respondents who are working but in precarious positions

and even worse for those individuals who are seeking employment.

Among the 80% of respondents who were working in non-precarious jobs that reported having extended health care coverage, nearly all had prescription drug coverage, dental coverage and coverage for other medical professionals.

Not having extended health care coverage is a significant source of stress and frustration for many respondents. The following quotes demonstrate their concerns:

“A universal drug plan!!! Private health insurance that won't exclude existing conditions!!! HIV meds, as you know, are expensive. For the first time in my life, I recently lost employment due to a restructuring. Along with losing my job, my drug coverage went with it. My spouse does not have insurance through his company. I'm very concerned about being able to afford my life-saving medications and making ends meet at home. At this time, I've even begun thinking of selling my home so that I will be able to pay for medication. That is not right. (Male, 35-44 years, depression, HIV/AIDS)

“More drug coverage should be offered through OHIP or somewhere for those of us who work contracts and can't get extended benefits. The plans you can purchase (like Manulife cover-me plan) doesn't often meet the needs of many of us. It's frustrating. More permanent employee positions are needed so that more of us can have extended health benefits and job security. Contract work is so stressful and it's getting harder and harder to find [a permanent] employee position.” (Female, 25-34 years, anxiety, chronic pain, depression)

Impact – Perceived under-employment among active labour force participants

Respondents who were active labour force participants were asked two questions about under-employment – one dealing with the ability to use all of her/his education, training and skills and the other, a direct question that asked if current or previous job required her/his level of education. Among respondents employed in permanent (non-precarious) jobs, 66% said the current job gives them the opportunity to use all of their education, training and skills and among respondents in precarious employment, the percentage was similar – 64%. The reverse was true for respondents who were seeking employment; only 33% reported that their last job allowed them to use all of their education, training and skills.

When asked if their current job /last job required the level of education that they had, the majority in all three categories said that it did. However, among those individuals who were employed (permanent and precarious), 22% and 24% respectively said they are over-qualified for their current position. Among respondents who are seeking employment, 49% said they were over-qualified for their last job.

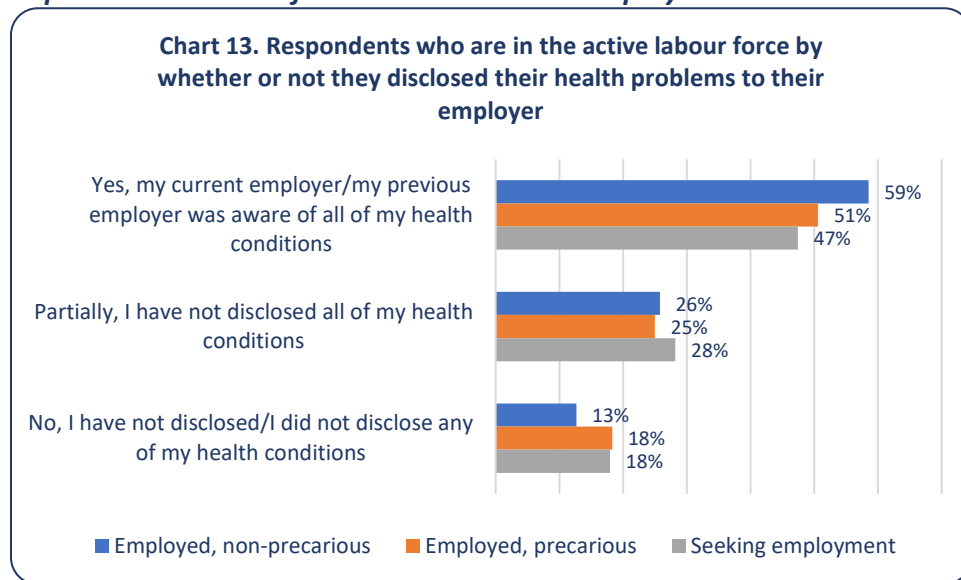
Respondents provided these insights:

“My life would be better if I could get employment in my field (Biomedical Engineering). I have a lot of skills and knowledge that is not being utilized. A job in my field would give me purpose and goals to strive for.” (Female, 35-44 years, multiple sclerosis, obsessive-compulsive behaviour)

“I want to work, but I physically cannot work full-time, which means I often have to work well below my education level and I am eternally short of money because I only work part-time. I try to push myself to work more, but then I get sick and this often results in unhappy employers.” (Female, 35-44 years, epilepsy, migraines)

“My survey shows that my current work is very accommodating (which it is) which is why I can work there. However, it is not what want to be doing and does not make use of my education and training. The last jobs that did make use of my education and training (university setting scientific research and university sessional instruction) were very unaccommodating.” (Female, 35-44 years, migraines, irritable bowel syndrome)

Impact – Disclosure of health conditions to employer



Of the 671 participants who were active labour force participants, 58% reported that they disclosed all of their health conditions to their current employer (for persons who are currently employed) or to their last employer (for persons who are unemployed

and actively seeking employment. There are differences among the three populations with respondents who are in non-precarious jobs having the highest – 59% dropping to 51% among respondents in precarious jobs and below half (47%) among individuals who are actively seeking employment.

• **Respondents in non-precarious (permanent) jobs**

The 268 respondents who were employed in non-precarious jobs who reported that they disclosed all of their health conditions to their employers had a different mix of chronic conditions than those individuals who partially disclosed and those individuals who did not disclose at all.

Table 3. Respondents employed in non-precarious (permanent) jobs, by whether or not they disclosed their health conditions to their employer

Episodic health condition	Number of respondents	Yes, my current employer/my previous employer was aware of all of my health conditions	Partially, I have not disclosed all of my health conditions	No, I have not disclosed/I did not disclose any of my health conditions	Did not respond/prefer not to answer
Anxiety	201	45%	35%	18%	2%
Arthritis	100	60%	27%	10%	3%
Asthma	55	53%	40%	7%	0%
Chronic pain	92	49%	38%	12%	1%
Crohn's disease/ulcerative colitis	85	71%	24%	5%	0%
Depression	170	47%	35%	16%	2%
Migraines	92	55%	30%	11%	4%
Multiple sclerosis	50	78%	8%	8%	6%
Total respondents	458	59%	26%	13%	2%

The majority of respondents (85%) disclosed or some of their conditions to their employer. Respondents with multiple sclerosis or Crohn's disease/ulcerative colitis were more likely than average to disclose – 78% who have multiple sclerosis and

71% who have Crohn's disease/ulcerative colitis. By contrast, only 45% who have anxiety, 47% who have depression and 49% who have chronic pain disclosed all of their conditions to their employer.

Just over one in four among respondents who are in permanent positions disclosed only some of their health conditions. Over half (58%) of these respondents did not disclose their mental health condition. Another 10% said that they did not disclose the actual condition but talked in vague terms of having a condition or disclosed symptoms.

Thirteen percent of respondents who were in permanent jobs disclosed none of their health conditions to their employers. As Table 3 shows, the percentage was higher among persons who reported anxiety and/or depression as one of their episodic health conditions.

When asked how supportive their employer was after disclosure, 58% of respondents in non-precarious jobs said "very supportive", 34% said "somewhat supportive" and 8% said "not supportive at all".

• **Respondents in precarious jobs**

Table 4. Respondents employed in precarious jobs, by whether or not they disclosed their health conditions to their employer

Episodic health condition	Number of respondents	Yes, my current employer/my previous employer was aware of all of my health conditions	Partially, I have not disclosed all of my health conditions	No, I have not disclosed/I did not disclose any of my health conditions
Anxiety	67	34%	33%	25%
Arthritis	33	64%	24%	9%
Chronic pain	25	32%	44%	12%
Crohn's disease/ulcerative colitis	26	77%	8%	15%
Depression	45	36%	19%	19%
Migraines	21	48%	30%	11%
Multiple sclerosis	20	55%	15%	30%
Total respondents	164	51%	25%	18%

The prevalence of an episodic health condition among respondents in precarious jobs is similar to those in non-precarious jobs. However, the willingness to disclose is different for some conditions. While overall, 51% of respondents in precarious jobs disclosed all of their conditions, only 34% of

them with anxiety, 32% with chronic pain and 36% with depression disclosed their condition. It is interesting to note these percentages were much less than among respondents in non-precarious jobs.

When asked how supportive their employer was after disclosure, the responses were much different from those received by respondents in non-precarious jobs. Only 25% of respondents in precarious jobs said “very supportive” compared to 58% of respondents in non-precarious jobs, 53% said “somewhat supportive” compared to 34% of respondents in non-precarious jobs and 13% said “not supportive at all” compared to 8% of respondents in non-precarious jobs.

Awareness of health conditions by co-workers

Respondents were asked if their co-workers are/were aware of their episodic health condition(s). Among the 447 respondents who answered the question and who had a non-precarious job, only 7% reported that their co-workers are unaware of their health conditions. This percentage doubled to 14% among the 151 respondents who had precarious jobs and among the 71 respondents who are actively seeking employment.

When asked if awareness of health conditions created any challenges in the workplace for the respondent, 56% of respondents in both non-precarious and precarious jobs reported that it did. This percentage increased to 71% among respondents who are actively seeking employment.

When asked if co-workers are/were supportive in terms of the respondents’ health condition(s), 88% of respondents in non-precarious jobs and 86% of respondent in precarious jobs reported very or somewhat supportive; among respondents who are actively seeking employment, this dropped to 74%.

Accommodation in the workplace – employed in permanent jobs (non-precarious)

Of the 447 respondents who are employed in non-precarious jobs and who answered the questions on workplace accommodation, 26% reported that they needed no job accommodation and 4% did not answer the question. Among the remaining 313 respondents,

- 31% got everything that they asked for;
- 33% got some of what they asked for;
- 26% needed accommodation but did not ask their employer; and
- 10% asked but did not get the accommodation.

Breaking down the information by episodic condition highlights some very interesting differences. Respondents who reported PTSD were less likely to report that they did not need an accommodation and much more likely to report that they were getting only some of what they asked for. They were also more likely to need but not ask for an accommodation. By contrast, people who reported having multiple sclerosis were more likely not to need an accommodation, more likely to get what they need and much less likely not to ask for what they needed.

Partial and total unmet needs are highest among people reporting arthritis, Crohn's disease/ulcerative colitis, chronic pain, migraines and PTSD. Totally met needs are highest among persons reporting multiple sclerosis and chronic pain.¹ This condition was always reported in conjunction with other chronic health conditions

These relationships will be explored in more detail on the fact sheets that will be prepared on each episodic condition.

¹ It should be noted that no respondent reported chronic pain only which is why chronic pain appears in both groups – those with partially and total unmet needs and those with totally met needs.

Table 5. Need for workplace accommodation by reported episodic health condition, for persons in permanent jobs (non-precarius)							
	Need for workplace accommodation						Total
	No, I do not need any accommodation	Yes, I need accommodation and I am getting all that I asked for	Yes, I need accommodation and I am getting some of what I asked for	Yes, I need accommodation but I have not asked my employer	Yes, I need accommodation but my employer has not provided it/them	Prefer not to answer	
Total	26.2%	22.4%	22.6%	17.9%	6.7%	4.3%	447*
Anxiety	24.2%	20.7%	22.7%	20.2%	5.6%	6.6%	198
Depression	23.7%	22.5%	23.1%	18.9%	6.5%	5.3%	169
Arthritis	21.4%	21.4%	25.5%	18.4%	10.2%	3.1%	98
Chronic pain	16.7%	27.8%	30.0%	16.7%	6.7%	2.2%	90
Migraines	23.6%	20.2%	27.0%	13.5%	10.1%	5.6%	89
Crohn's disease and Ulcerative Colitis	23.8%	17.9%	26.2%	21.4%	6.0%	4.8%	84
Multiple Sclerosis	31.3%	31.3%	25.0%	8.3%	4.2%	0.0%	48
Post-traumatic stress disorder	15.9%	20.5%	34.1%	22.7%	2.3%	4.5%	44

* There were 11 respondents who did not answer the questions on workplace accommodation.

The type of the accommodations sought were primarily limited to four – job redesign, modified hours or days or reduced hours, a modified or ergonomic workstation, and a special chair or back support.

For job redesign (modified or different duties), out of 296 respondents who answered the question,

- 57% said they did not need it;
- 15% said they got everything that they asked for;
- 17% said they got some but not all of what they asked for; and
- 12% said they did not get any of what they asked for.

For modified hours or days or reduced work hours, out of 299 respondents who answered this question,

- 22% said they did not need it;
- 32% said they got everything that they asked for;
- 25% said they got some but not all of what they asked for; and
- 20% said they did not get any of what they asked for.

For a modified or ergonomic workstation, out of 292 respondents who answered this question,

- 57% said they did not need it;
- 20% said they got everything that they asked for;

- 13% said they got some but not all of what they asked for; and
- 11% said they did not get any of what they asked for.

For a special chair/back support, out of 288 respondents who answered this question,

- 64% said they did not need it;
- 22% said they got everything that they asked for;
- 6% said they got some but not all of what they asked for; and
- 8% said they did not get any of what they asked for.

Some respondents indicated in the “other type of accommodation” that they needed scent-free work areas and ability to work from home (telework).

Accommodation in the workplace – employed in precarious jobs

Because of limitations in sample size, there is limited detail that can be provided with respect to accommodation for the segment of people who are employed in jobs that are precarious. Of the 164 respondents who reported that their employment was precarious,

- 30% reported that they needed no job accommodation;
- 20% got everything that they asked for;
- 19% got some of what they asked for;
- 16% needed accommodation but did not ask their employer;
- 7% asked but did not get the accommodation; and
- 8% said that they preferred not to answer the question or did not answer the question.

5.5 What is the financial impact of having an episodic health condition?

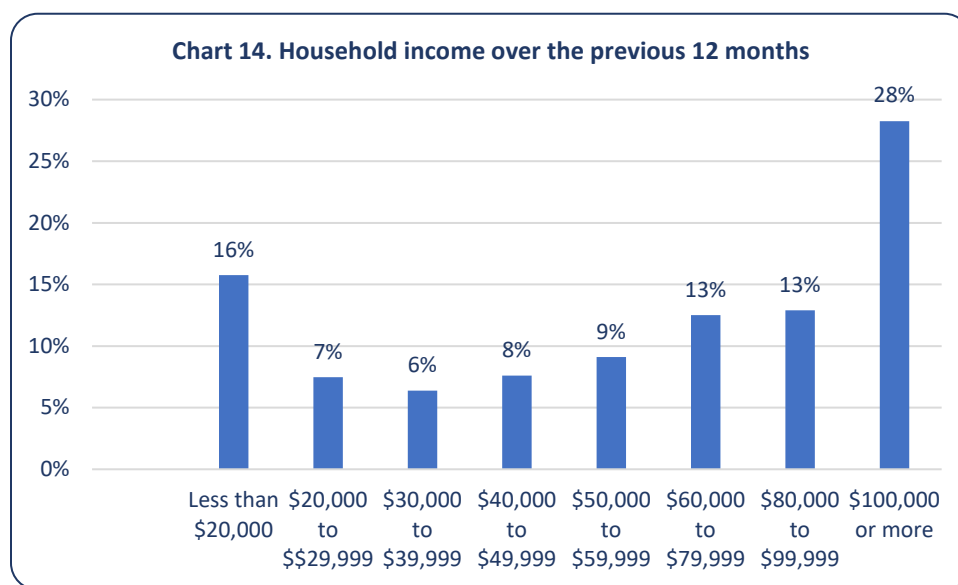
Personal income

Table 6. Personal income over the past 12 months, by employment status

Personal income (before taxes and deductions) over the past 12 months	Employment status				Total
	Employed, non-precarious	Employed, precarious	Seeking employment	Not in the labour force	
No personal income	0%	1%	11%	19%	7%
Less than \$20,000	9%	26%	58%	46%	29%
\$20,000 to \$29,999	6%	20%	9%	7%	10%
\$30,000 to \$39,999	10%	15%	2%	10%	12%
\$40,000 to \$49,999	17%	12%	9%	5%	14%
\$50,000 to \$59,999	17%	8%	5%	7%	14%
\$60,000 to \$79,999	20%	9%	5%	3%	15%
\$80,000 to \$99,999	13%	5%	2%	3%	9%
\$100,000 or more	9%	4%	0%	2%	6%
Total	397	137	64	196	794

Of the 953 respondents, 794 answered the question on personal income. Among those who responded, 15% had income of \$80,000 or more (before taxes and deductions) in the previous 12 months. By contrast, 36% had less than \$20,000.

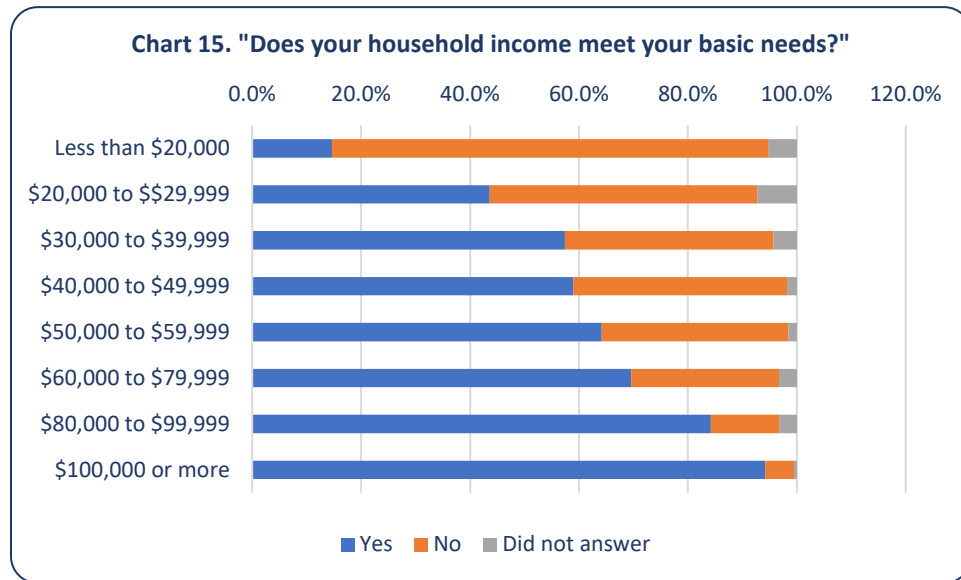
There are major differences when income by employment status is explored. Among the 397 respondents who are in non-precarious jobs, 22% had personal income of \$80,000 or more while 9% had income less than \$20,000. Among the three other employment statuses, the reported income distribution was much different. Among the 137 respondents who were employed in precarious jobs, only 9% had incomes of \$80,000 or more and 47% had personal income of less than \$20,000. The situation was much worse among respondents who were seeking employment – only 2% had personal incomes of \$80,000 or more while 75% had personal incomes of less than \$20,000. Among respondents who were not in the active labour force, the corresponding percentages were 5 and 72.



Of the 953 respondents, 736 provided total income data. Among those who did report, 41% reported total household income of \$80,000 or more while 29% reported household income of under \$40,000.

When asked if the household income met their basic needs, 31% said that it did not.

When asked if the household income



Not surprising, as household income increased, a positive response to “Does your household income meet your basic needs?” increased from 15% among respondents who reported a household income of less than \$20,000 to 94% among respondents with a

household income of \$100,000 or more.

5.6 What do you find the most challenging about living with your chronic health condition(s)?

There were 777 respondents who provided an answer to this question. Some responses were short and to the point “Very isolating condition”, “Working through fatigue and pain”, “unpredictable”, “uncertainties”. Others provided a detailed description of their life – in the past, as it is today and fear for the future. Respondents reported the following:

1. the **physical impact** (270) – the impact of their pain and/or fatigue, the side effects of their medication, loss of mobility and finding a toilet;
2. the **unpredictability** (251) – being unable to plan or commit to anything, uncertainty of what to expect, makes living a constant struggle and creates problems in the workplace;
3. the **work implications** (215) – not being able to work, losing job/career, being under-employed/under paid, being demoted/having to change jobs, having to work when ill, lack of accommodation in the workplace (flex time, work from home), lack of sick days, job stagnation/no ability to advance, attitudinal barriers and unsupportive employers/co-workers;
4. the **personal impact** (144) – losing autonomy, dependence on others, loss of driver’s licence, experiencing stigma and discrimination;
5. the **emotional impact** (134) – anxiety, depression, frustration, stress, being overwhelmed, embarrassment, shame and thoughts of suicide;
6. the **invisibility** of their condition(s) (128) – others cannot see “it” and therefore do not believe or understand and needing to constantly provide an explanation to others;
7. their **quality of life** (105) – loss of activities that brought joy (gardening, travel, sports), “being able to do what I want to do” and having the energy only to work (work/life balance);
8. **being poor** (101) – cannot find affordable housing, financial strain of trying to make ends meet, always having to make choices between basics;

9. **navigating the system** (98) – social assistance rules, CPP-D, long waiting lists, having to self-advocate;
10. the impact on **relationships** (77) – their children, their spouse/partner, relatives and friends; and
11. the **additional expenses** (61) – for prescriptions, treatments and special foods.

5.7 “What do you think could be done to improve your quality of life?”

There were 707 respondents who answered this question and 200 respondents either said they had no suggestions or it was too personal and preferred not to provide. The remaining 507 respondents provided some concrete suggestions as to how their quality of life could be improved.

- **Improved experience in the workplace** (214) – increased awareness by employers of episodic health conditions, workplace accommodations such as flexible work hours, more sick days, help in finding suitable work;
- **Disability supports** (132) – stress reduction programs, supports for family/spouse, increased supports generally, improvement in existing support programs;
- **Changes to the health care system** (122) – easier access to health care professionals including specialists, more training of health care professional concerning people with multiple and complex medical conditions, increased health benefits, better funding for mental health supports, better medications, expansion of assisted death legislation;
- **Disability system** (116) – increased awareness of episodic disability, more understanding by insurance companies of episodic disabilities, more research concerning particular health conditions, more public washrooms, more accessible public spaces;
- **Income support** (57) – increase welfare payments, have a guaranteed basic income, financial security, increase benefit rates; and
- **Assistance with expenses** – (40) – affordable access to exercise programs, help with the cost of medications and treatments, help with cost of schooling and retraining, help with cost of transportation.

5.8 “Is there anything else that you would like to share about your experience living with your episodic health condition(s)?”

There were 448 respondents who provided an answer to this question with 202 saying that it was personal and they did not want to share or that they just did not know. Much of what the remaining 246 respondents answered mirrored what had been said in their response to the previous question. Summarized, the majority of their responses dealt with:

- changes in the **workplace** (221) – increased awareness of what an episodic or invisible health condition is, removing attitudinal barriers, reducing stress in the workplace, more sick days, improving workplace accommodation to include flex time and ability to work from home, help finding employment and support with retraining;

- changes to the **health care and sickness support systems** (211) – increased awareness of what an episodic health condition is among all officials associated with programs and services, improvement in health care coverage to include medications and treatments, increased funding for awareness training, increased funding for research, easier and faster access to health care specialists and improved coverage for short- and long-term disability;
- **increased awareness** (80) in general society about what an episodic health condition is; and
- changes to the **income support system** (57) – increased welfare payments to realistically cover living expenses, removal of barriers to CPP-D concerning episodic health conditions, creation of a guaranteed income and financial security.

6. Conclusion and next steps

The results from this new survey provide further insights into the impact of living with an episodic health condition. While the focus of the report is on the impact that these conditions have on employment, we hear from the respondents that the impact touches on all aspects of their life. Issues identified include:

- **increased awareness** of what it means to live with an episodic health condition. This lack of awareness was seen in friends and family members, health professionals, employers and co-workers, disability-support program officials and disability service providers.
- **increased income support** through provision of a basic income, expansion of CPP-D coverage to include episodic health conditions, more affordable housing, more affordable transportation, more affordable exercise programs.
- **improved health coverage** including better access to medications and treatments including medical marijuana, increased funding for mental health supports, better access to support groups, easier and faster access to specialists or treatments.
- **improved conditions in the labour market** including availability of health care benefits for persons in precarious jobs, increased supports in obtaining training and re-training, increased awareness of the accommodations required to support the hiring and retention of persons with episodic health conditions.
- **improved conditions in the workplace** including improved leave policies to accommodate intermittent work capacity, increased awareness of the nature and extent of “soft” accommodations required to support persons with episodic health conditions, development of guidelines concerning disclosure. The findings outlined in this report advance the emerging literature on episodic disability and employment summarized in Section 5.4. Building on the seminal work of Antae *et al.* (2013), Lysaght *et al.* (2011), Smith Fowler *et al.* (2011) and Vick (2012, 2014), this survey provides further insights into the issue of precarious/non-precarious employment, disclosure of health conditions to employers, and attitudes of co-workers.

This report is the first in a series of products that will disseminate the findings from the survey. A series of short profiles will be developed in April that will focus on particular health conditions. A paper is being developed for submission to a peer-reviewed journal. An “impact” index will be developed based on the data derived from life roles questions.

Further analysis is planned to exploit the wealth of data contained in the three open-ended questions concerning disclosure and accommodations. This information will be used to formulate questions that will be asked of employers in the next phase of “Learning from Each Other”.

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Appendix A. Some demographic details

Variable	Category	Frequency	Percent
Total		953	100%
Gender	Female	727	76%
	Male	166	17%
	Other (please specify)	19	2%
	Prefer not to answer/no response	41	4%
Age	Under 15 years	2	0%
	15 to 24 years	57	6%
	25 to 34 years	181	19%
	35 to 44 years	259	27%
	45 to 54 years	240	25%
	55 to 64 years	141	15%
	65 year and older	37	4%
	Prefer not to answer/ no response	36	4%
Province or territory	Newfoundland and Labrador	17	2%
	Prince Edward Island	4	0%
	Nova Scotia	43	5%
	New Brunswick	14	1%
	Quebec	118	12%
	Ontario	412	43%
	Manitoba	29	3%
	Saskatchewan	29	3%
	Alberta	94	10%
	British Columbia	129	14%
	Yukon	1	0%
	Northwest Territories	4	0%
	Prefer not to answer/ no response	59	6%
Highest level of education	Less than a high school diploma or its equivalent	29	3%
	High school diploma or a high school equivalency certificate	113	12%
	Trade certificate or diploma	59	6%
	College, CEGEP or other non-university certificate or diploma (excluding trade certificate or diploma)	199	21%
	Bachelor's degree (e.g.- B.A., B. Sc., LL.B)	218	23%
	University degree or diploma below the bachelor's level	80	8%
	University certificate, diploma or degree above the bachelor's level	216	23%
	Don't know/Prefer not to answer	39	4%

Appendix B List of Organizations

1. The Arthritis Society:
2. Canadian Lung Association
3. Asthma Society of Canada
4. Canadian Cancer Society
5. The Lung Society
6. Asthma Society of Canada
7. Chronic Pain Association of Canada
8. GBS/CIDP Foundation of Canada
9. Crohns and Colitis Canada
10. Canadian Diabetes Association
11. Epilepsy Canada
12. Action Hepatitis Canada
13. Realize Canada
14. Lupus Canada
15. Canadian Mental Health Association
16. Mood Disorders Society of Canada
17. Canadian Mental Health Commission
18. Psychiatric Survivors of Ottawa
19. Multiple Sclerosis Society of Canada
20. www.menieres-disease.ca
21. Parkinson Society Canada
22. www.headachenetwork.ca
23. Neurological Health Charities Canada

Appendix C Backgrounder and Sample Tweets

Backgrounder - English

LEARNING FROM EACH OTHER: BEST PRACTICES IN HIRING AND RETAINING PEOPLE WITH EPISODIC CONDITIONS

A team of community based researchers are conducting a study on the experiences with people living with health conditions that result in unpredictable periods of health and illness. The information will be used to develop resources to improve employment opportunities for people with episodic conditions. During October-December 2016 they are inviting people living with episodic conditions to complete an online survey and share their experience with daily activities including work.

FOR MORE INFORMATION, CLICK
<https://www.surveymonkey.com/r/epidis2016>

Backgrounder – French

APPRENDRE LES UNS DES AUTRES : MEILLEURES PRATIQUES POUR L’EMBAUCHE ET LA RÉTENTION DE PERSONNES ATTEINTES DE MALADIES ÉPISODIQUES

Une équipe de chercheurs communautaires effectue une étude sur le vécu de personnes souffrant de problèmes de santé entraînant des périodes imprévisibles de bonne santé et de maladie. L’information sera utilisée pour élaborer des ressources qui permettront d’améliorer les possibilités d’emploi pour les personnes atteintes de maladies épisodiques. D’octobre à décembre 2016 les chercheurs invitent ces personnes à répondre à un questionnaire en ligne et à parler de leur expérience des activités quotidiennes, dont le travail.

POUR PLUS DE RENSEIGNEMENTS, CLIQUER
<https://fr.surveymonkey.com/r/incepi2016>

Sample Tweets – English

These tweets will be modified as appropriate and sent out by our community partners. The findings being reported are from phase one of this project, and are based on findings from our analysis of episodic disability from the Canadian Survey on Disability (Statistics Canada).

1. If you live with an episodic health condition, pls take our survey. #EpisodicDisabilitySurvey <http://bit.ly/epd2016>
2. CPP-D excludes people w episodic disabilities due to 'prolonged' criteria. Take our survey.#EpisodicDisabilitySurvey <http://bit.ly/epd2016>
3. Many people with episodic disabilities are not covered by EI Sickness benefits. Take our survey! <http://bit.ly/epd2016>
4. Many people with episodic disabilities don't meet CPP-D's definition of disability. Take our survey! <http://bit.ly/epd2016>
5. Many people w episodic disability can't access the Disability Tax Credit.Take our survey! <http://bit.ly/epd2016> #EpisodicDisabilitySurvey

6. 4 out of 5 Canadians with disabilities report an episodic health condition as either their 1st or 2nd condition. <http://bit.ly/epd2016>
7. Work disability may have a bigger impact on employment than an episodic health condition. Help us learn more! <http://bit.ly/epd2016>
8. People with episodic disabilities report that they have been discriminated against at work. Take our survey! <http://bit.ly/epd2016>
9. People w episodic disabilities worry about return to work because they can lose access to housing. Take our survey <http://bit.ly/epd2016>
10. People w episodic disability worry about return to work because they can lose access to drug plans. Take our survey <http://bit.ly/epd2016>
11. Some employers have what it takes to successfully navigate the complexities of working with an episodic health condition. <http://bit.ly/epd2016>
12. Does your employer have what it takes to successfully navigate intermittent work capacity? Take our survey! <http://bit.ly/epd2016>
13. Some employers have what it takes to navigate the complexities of working with an episodic health condition - yours? <http://bit.ly/epd2016>
14. HIV, MS, Arthritis. If you live w an episodic health condition take our survey!

Sample Tweets – French

Ces gazouillis seront modifiés comme nécessaire et envoyés à nos partenaires communautaires. Les résultats rapportés proviennent de la première phase de ce projet et de notre analyse des constatations sur l'incapacité épisodique dans l'Enquête canadienne sur l'incapacité (Statistique Canada).

1. Si vous souffrez d'une maladie épisodique, participez à notre enquête svp. #Enquêtesurlesincapacitésépisodiques http://bit.ly/iep_2016
2. 1 incapacité épisodique ne donne pas droit aux PPI-RPC #Enquêtesurlesincapacitésépisodiques http://bit.ly/iep_2016
3. l'invalidité n'est pas « prolongée ». Participez à notre enquête. #Enquêtesurlesincapacitésépisodiques http://bit.ly/iep_2016
4. Bcp de gens souffrant 2 maladies épisodiques ne touchent pa 2 prestations maladie 2 l'AE Participez à notre enquête! http://bit.ly/iep_2016
5. incapacités épisodiques diffèrent 2 la déf.2 l'incapacité pr les PPI-RPC. Répondez à notre questionR! #Enquêtesurlesincapacitésépisodiques
6. incapacités épisodiques diffèrent 2 la déf.2 l'incapacité pr les PPI-RPC. Répondez à notre questionR! http://bit.ly/iep_2016
7. Plein 2 gens ac 1 incapacité épisodique n'ont pa accès au crédit d'impôt pr personnes handicapées http://bit.ly/iep_2016
8. Participez à notre enquête! http://bit.ly/iep_2016 #Enquêtesurlesincapacitésépisodiques
9. 4 Canadiens sur 5 citent une maladie épisodique comme 1e ou 2e maladie. http://bit.ly/iep_2016

10. L'incapacité au travail pourrait avoir plus d'impact sur l'emploi qu'une maladie épisodique. Aidez-nous à comprendre! http://bit.ly/iep_2016
11. Des gens ac 1 incapacité épisodique parlent de discrimination contre eux au travail. Répondez à notre questionnaire! http://bit.ly/iep_2016
12. Des gens ac 1 incapacité épisodique craignent 2 perdre l'accès au logement en reprenant le travail http://bit.ly/iep_2016
13. Participez à notre enquête! http://bit.ly/iep_2016
14. Des gens avec une incapacité épisodique ont peur de perdre l'accès à l'assurance-médicaments en reprenant le travail.http://bit.ly/iep_2016

Appendix D Survey Questionnaire

1. Learning from each other: Living with an episodic health condition

BACKGROUND INFORMATION

Research Team:

Rebecca Gewurtz (McMaster University), Adele Furrie (Adele Furrie Consulting Inc.), John Stapleton (Open Policy Ontario), Wendy Porch (Canadian Working Group on HIV and Rehabilitation), Maureen Haan (Canadian Council on Rehabilitation and Work)

Sponsor:

Office for Disability Issues (Employment and Social Development Canada)

Purpose:

The purpose of this research is to explore the experiences of people living with health conditions that result in unpredictable periods of health and illness. The information will be used to develop resources to improve employment opportunities for people with episodic conditions. The survey will take approximately 20-30 minutes to complete.

Are there any risks to participating in this survey?

There are no risks involved in participating in this survey. Please be aware that you do not need to answer questions that you do not want to answer or that make you feel uncomfortable. You can withdraw (stop taking part) by exiting the survey. If you do stop the survey before completion, none of your responses will be kept. At the end of the survey, please click the "Submit" so that your responses will be recorded.

Please note that you will not be asked to provide your name or other identifiable information in the survey.

Please select one of the following:

- I have read the information and I agree to participate in the survey.
- I have read the information and I do NOT agree to participate in the survey.

2. Your health condition(s)

Thank you for taking time to complete this survey about the impact of living with a chronic health condition that results in periods of wellness and periods of illness. We are very appreciative of your willingness to share your life experience with us.

What are your health conditions?

- Anxiety
- Arthritis
- Asthma
- Bi-polar disorder
- Cancer
- Chronic obstructive pulmonary disease (including chronic bronchitis and emphysema)
- Chronic pain
- Chronic inflammatory demyelinating polyneuropathy (CIDP)
- Crohn's disease and Ulcerative Colitis
- Depression
- Diabetes
- Epilepsy
- Hepatitis C
- HIV/AIDS
- Lupus
- Meniere's Disease
- Multiple Sclerosis
- Migraines
- Parkinson's Disease
- Post-traumatic stress disorder
- Substance abuse disorder

Any other diseases or health conditions - please specify

What do you consider to be the health conditions that have the most impact on your daily activities? (Choose one only)

I have only one condition that impacts on my ability to do my daily life activities and it is

I have more than one condition that impacts on my ability to do my daily life activities and they are

3. Now we want to ask a few questions about impact.

We now want to know about the impact your health condition(s) has/have on your daily activities in terms of predictability, frequency and intensity.

Which of the following best describes the predictability of the impact of your condition(s) have on your ability to do your daily activities?

- It is similar from day to day
- It changes in unpredictable ways

Is your ability to do your daily activities

- Getting better
- Getting worse
- Staying the same
- It varies too much to choose one category
- Prefer not to answer

How many episodes did you have in the past 12 months that negatively impacted on your ability to do your daily activities?

How long do these episodes "typically" last?

- Less than a day
- 1-2 days
- 3-7 days
- 8-14 days
- 15-30 days
- More than one month
- Unable to choose a category because length of episodes varies too much
- Prefer not to answer

4. Continuing on with impact

Thinking about your various life roles

.... how often does your health condition(s) affect your ability to participate in paid work or in a business?

- never
- rarely
- sometimes
- often
- always
- my health condition(s) is/are the reason why I do not work
- I do not work for reasons other than my health condition(s)
- prefer not to answer

..... your role as a parent?

- never
- rarely
- sometimes
- often
- always
- my health condition(s) is/are the reason that I am not a parent
- I am not a parent for reasons other than my health condition(s)
- prefer not to answer

.... your role as a spouse/partner?

- never
- rarely
- sometimes
- often
- always
- my health condition(s) is/are the reason that I am not in a relationship
- I am not in a relationship for reasons other than my health condition(s)
- prefer not to answer

.... your capacity to attend school/training?

- I've finished with school/training
- never
- rarely
- sometimes
- often
- always
- my health condition(s) is/are the reason why I do not attend school/participate in training
- I do not attend school/participate in training for reasons other than my health condition(s)
- prefer not to answer

.... your ability to volunteer or participate in community activities?

- never
- rarely
- sometimes
- often
- always
- my health condition(s) is/are the reason why I do not volunteer/ or participate in community activities
- I do not volunteer or participate in community activities for reasons other than my health condition(s)
- prefer not to answer

.... your ability to provide care to others?

- never
- rarely
- sometimes
- often
- always
- my health condition(s) is/are the reason why I do not provide care to others
- I do not provide care to others for reasons other than my health condition(s)
- prefer not to answer

.... your ability to participate in passive leisure activities such as reading, watching TV, etc.?

- never
- rarely
- sometimes
- often
- always
- my health condition(s) is/are the reason why I do not participate in leisure activities
- I do not participate in leisure activities for reasons other than my health condition(s)
- prefer not to answer

.... your ability to participate in physical activities/exercise?

- never
- rarely
- sometimes
- often
- always
- my health condition(s) is/are the reason why I do not participate in physical activities/exercise
- I do not participate in physical activities/exercise for reasons other than my health condition(s)
- prefer not to answer

5. We are now interested in learning about your work experience.

What best describes your current employment status? Are you

- Self-employed
- Employed full-time (30 hours or more per week) **and** my job is permanent
- Employed full-time (30 hours or more per week) **and** my job is seasonal
- Employed full-time (30 hours or more per week) **and** my job is term/contract
- Employed part-time (less than 30 hours per week) **and** my job is permanent
- Employed part-time (less than 30 hours per week) **and** my job is seasonal
- Employed part-time (less than 30 hours per week) **and** my job is term/contract
- Temporarily laid off
- Seeking employment
- Not looking for work but able to work
- Retired
- Completely prevented from working because of my health condition(s)
- Don't know/prefer not to answer

6. Continuing with your work experience

Have you ever worked?

- Yes
- No
- Prefer not to answer

7. Continuing on with your work experience

When did you last work?

What was/were the reason(s) that you stopped working?

- My health is the reason why I am not working
- I am not working for reasons other than my health
- Prefer not to answer

Other (please specify)

8. Continuing with your work experience

On average, hours many hours a week do you work?

- 1-9 hours
- 10-19 hours
- 20-29 hours
- It varies too much from week to week to come up with an average
- prefer not to answer

9. Some details about your present job

When did you start this job?

How certain are you that you will have this job in two years?

- Very certain
- Somewhat certain
- Not certain at all
- Prefer not to answer

10. Continuing with your work experience

During episodes of illness, are you able to work?

- Yes, I can work my regular hours
- Yes, but I have to reduce my hours
- Sometimes I can, sometimes I cannot
- No, I am unable to work
- prefer not to answer

11. Continuing with your work experience

What is (was) your occupation? *(Please be as specific as possible, e.g. - secondary school teacher, store clerk, plumber.)*

What kind of business, industry or service is/was this? *(Please be as specific as possible, e.g. - municipal police, retail store federal government.)*

Do you have access to extended health care benefits?

- Yes
- No
- Prefer not to answer

12. And now, a question about extended health benefits.

What type of extended health benefits? *Please check all that apply.*

- Short-term disability
- Long-term disability
- Prescription drug coverage
- Dental coverage
- Other medical professionals such as physiotherapist, chiropractor
- Prefer not to answer

Other (please specify)

13. And

How many jobs have you had during the past year?

- None
- Only 1
- 2-5
- 6 or more
- prefer not to answer

14. And, about your multiple jobs

What was/were the reason(s) for having multiple jobs? *(check as many as apply to you.)*

I changed my jobs because of my health condition(s)

My jobs were contract/casual/term

Prefer not to answer

Other (please specify)

15. Continuing with your work experience ...

Because of your health condition(s), have you ever changed the *kind* of work you do?

- Yes
- No
- Prefer not to answer

Because of your health condition(s), have you ever changed the *amount* of work you do?

- Yes
- No
- Prefer not to answer

Because of your health condition(s), have you ever *changed your job*?

- Yes
- No
- Prefer not to answer

In the past five years, because of your health condition(s), have you ever tele-worked or worked from home?

- Yes
- No
- Prefer not to answer

Does your current job (if not now working, did your last job) give you the opportunity to use all your education, training and skills?

- Yes
- No
- Prefer not to answer

Does your current job (if not working, did your last job) require the level of education you have?

- Yes
- No, I am/was under-qualified
- No, I am/was over-qualified
- Prefer not to answer

Is your current employer (if not working, was your previous employer) aware of you health condition(s)?

- Yes, my current employer/my previous employer was aware of all of my health conditions
- Partially, I have not disclosed all of my health conditions
- No, I have not disclosed/I did not disclose any of my health conditions
- Prefer not to answer

16. And about your health conditions

What condition(s) did you NOT disclose?

17. And your employer

E17. How supportive is/was your employer in terms of your health condition(s)?

- Very supportive
- Somewhat supportive
- Not supportive at all
- Prefer not to answer

18. And your co-workers

Are/Were your co-workers aware of your health condition(s)?

- Yes, **all** of my co-workers know/knew about **all** of my health conditions
- Partly, **all** of my co-workers know/knew about **some** of my health conditions
- Partly, **some** of my co-workers know/knew about **all** of my health conditions
- Partly, **some** of my co-workers know/knew about **some** of my health conditions
- I have/had no co-workers
- No
- Prefer not to answer

19. Continuing about your co-workers

Has/Did this create any challenges for you in the workplace?

- Yes
- No
- Prefer not to answer

How supportive are/were your co-workers in terms of your health conditions?

- Very supportive
- Somewhat supportive
- Not supportive at all
- Prefer not to answer

20. Now, a few questions about job accommodation.

Thinking about your workplace, do you need/are you getting any accommodation to support you because of your health condition(s)? *By accommodation, we mean a back support for your chair, an accessible washroom, modified or different duties, flexible hours. Also, if you are not working now, answer about your last job.*

- No - I do not need any accommodation.
- Yes - I need accommodation(s) and I am getting all that I asked for.
- Yes - I need accommodation(s) and I am getting some of what I asked for.
- Yes - I need accommodation(s) but I have not asked my employer.
- Yes - I need accommodation(s) but my employer has not provided it/them
- Prefer not to answer

21. Accommodation

What type of accommodation and did you get it?

	Not needed	Needed and got everything that I needed	Needed but only got some of what I needed	Needed but did not get it
Job redesign (modified or different duties)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Modified hours or days or reduced work hours	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Human support, such as a reader, Sign language interpreter, job coach or personal assistant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Technical aids, such as a voice synthesizer, a TTY or TTD, an infrared system or portable note-takers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A computer with Braille, large print, voice recognition or scanner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Communication aids, such as Braille or large print reading material or recording equipment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A modified or ergonomic workstation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A special chair/back support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Handrails, ramps	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Appropriate parking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
An accessible elevator	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Accessible washroom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Accessible transportation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other (please specify what you needed and if you got it)

22. Now, three questions concerning your perception about your experience with discrimination.

In the past five years, do you believe that you have been let go from a job because of your health condition(s)?

- Yes
- No
- Prefer not to answer

In the past five years, do you believe that you have been refused an interview for a job because of your health condition(s)?

- Yes
- No
- Prefer not to answer

In the past five years, do you believe that your have been refused a job or a promotion because of your health condition(s)?

- Yes
- No
- Prefer not to answer

23. Now, we want to know a bit more about you.

What is your gender?

- Female
- Male
- Prefer not to answer
- Other (please specify)

What is your age?

- Under 15 years
- 15 to 24 years
- 25 to 34 years
- 35 to 44 years
- 45 to 54 years
- 55 to 64 years
- 65 year and older
- Prefer not to answer

Where do you live?

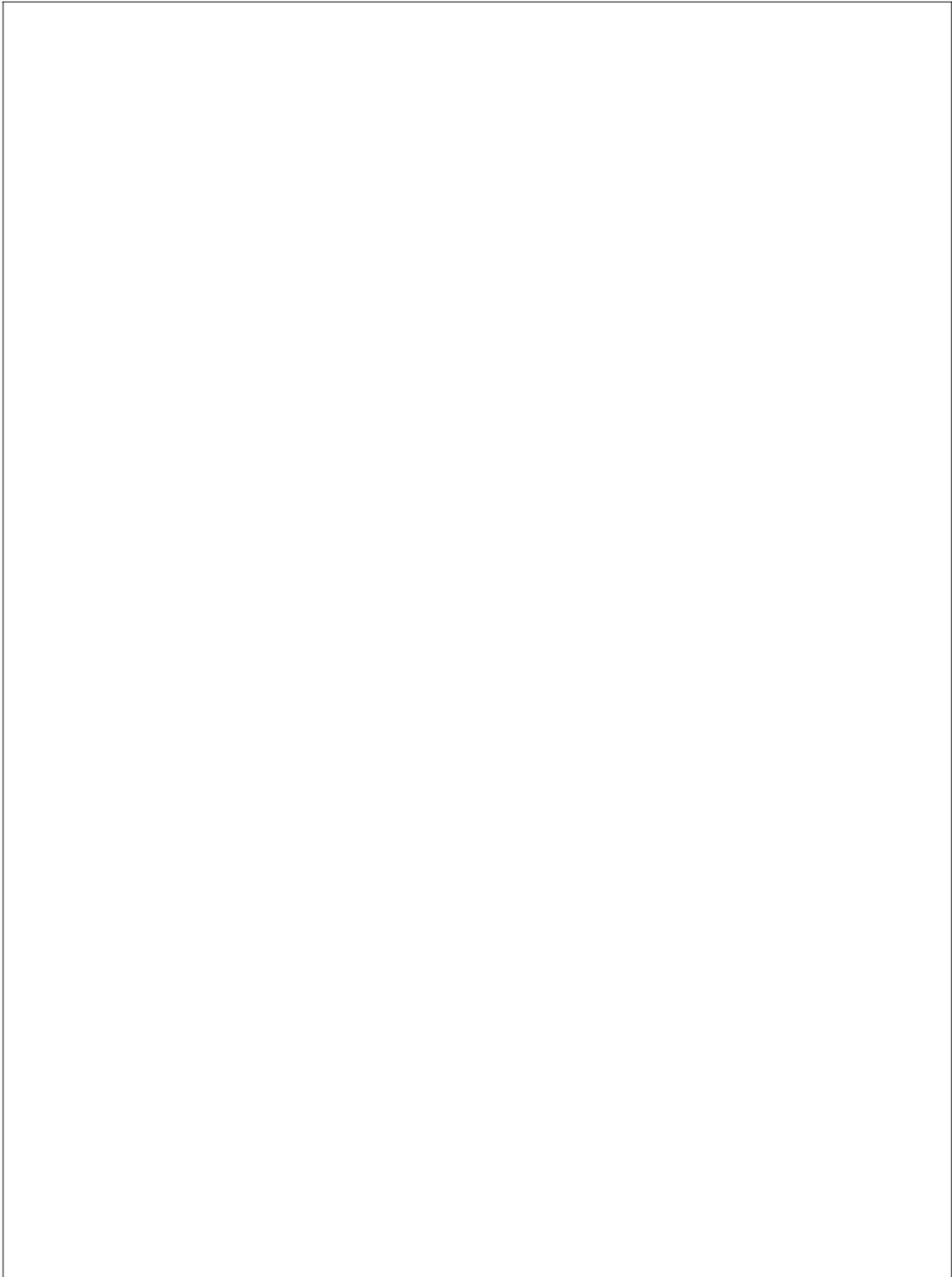
- Newfoundland and Labrador
- Prince Edward Island
- Nova Scotia
- New Brunswick
- Quebec
- Ontario
- Manitoba
- Saskatchewan
- Alberta
- British Columbia
- Yukon
- Northwest Territories
- Nunavut
- Prefer not to answer

In what type of community do you reside?

- Large urban centre (population of 100,000 or more)
- Medium urban centre (population between 30,000 and 99,999)
- Small urban centre (population between 1,000 and 29,999)
- Rural (population of 999 people or less)
- Prefer not to answer

What is your highest level of education?

- Less than a high school diploma or its equivalent
- High school diploma or a high school equivalency certificate
- Trade certificate or diploma
- College, CEGEP or other non-university certificate or diploma (*excluding trade certificate or diploma*)
- University degree or diploma below the bachelor's level
- Bachelor's degree (*e.g.- B.A., B. Sc., LL.B*)
- University certificate, diploma or degree above the bachelor's level
- Don't know/Prefer not to answer



24. And now, three questions about your economic situation

What is your estimate of your total personal income (before taxes and deductions) over the past 12 months?

- No personal income
- Less than \$20,000
- \$20,000 to \$29,999
- \$30,000 to \$39,999
- \$40,000 to \$49,999
- \$50,000 to \$59,999
- \$60,000 to \$79,999
- \$80,000 to \$99,999
- \$100,000 or more
- Prefer not to answer

What is your estimate of your total household income (before taxes and deductions) over the past 12 months?

- Less than \$20,000
- \$20,000 to \$29,999
- \$30,000 to \$39,999
- \$40,000 to \$49,999
- \$50,000 to \$59,999
- \$60,000 to \$79,999
- \$80,000 to \$99,999
- \$100,000 or more
- Don't know/Prefer not to answer

Does your household income meet your basic needs?

- Yes
- No
- Prefer not to answer

And now, some final comments.

What do you find the most challenging about living with your chronic health condition(s)?

What do you think could be done to improve your quality of life?

Is there anything else that you would like to share about your experience living with your health conditions?

25. Thank you

If you know of anyone else who is living with a health condition and who would be willing to complete this questionnaire, please forward the link to her/him. The more information we get, the more accurate the results will be.

Thank you so much for participating in this survey!

If you would like to receive a copy of our report, please send an e-mail to adfurrie@rogers.com and provide your name and e-mail address. We will be happy to share the report with you.

NOW, please hit the "Submit" button in the top right corner to submit your responses!

Incapacités épisodiques

1. Apprendre les uns des autres: Vivre avec une maladie épisodique

Information générale

Équipe de recherche :

Rebecca Gewurtz, Université McMaster, Adele D. Furrie, Adele Furrie Consulting Inc., John Stapleton, Open Policy Ontario, Maureen Haan, Conseil canadien de la réadaptation et du travail, Wendy Porch, Groupe de travail canadien sur le VIH et la réinsertion sociale,

Commanditaire :

Bureau de la condition des personnes handicapées (Emploi et Développement social Canada)

Objet :

L'objet de ce travail de recherche est de se pencher sur l'expérience des personnes atteintes de maladies chroniques entraînant une succession imprévisible de périodes de bonne santé et de périodes de maladie. L'information sera utilisée pour concevoir des ressources permettant d'améliorer les débouchés professionnels pour les personnes souffrant de maladies épisodiques. Le questionnaire prendra environ 20-30 minutes.

Y a-t-il des risques associés à la participation à cette étude?

Participer à cette étude ne comporte aucun risque. Veuillez noter que vous n'avez pas à répondre aux questions auxquelles vous ne voulez pas répondre ou qui vous mettent mal à l'aise. Vous pouvez vous retirer de l'étude (cesser d'y participer) en quittant la page du questionnaire. Si vous quittez le questionnaire avant d'avoir terminé, aucune de vos réponses ne sera enregistrée. À la fin du questionnaire, veuillez cliquer sur « Envoyer » pour que vos réponses soient enregistrées.

Veuillez noter qu'on ne vous demandera pas dans ce questionnaire de donner votre nom ou tout autre renseignement permettant de vous identifier.

Veuillez cocher l'une des réponses suivantes :

- J'ai lu l'information et le formulaire de consentement et j'accepte de participer à l'étude
- J'ai lu l'information et le formulaire de consentement et je REFUSE de participer à l'étude

Incapacités épisodiques

2. Votre/vos maladie(s)

Merci de prendre le temps de répondre à ce questionnaire sur l'impact qu'ont les maladies chroniques quand on a des périodes où on est bien et d'autres où on est malade. Nous vous sommes très reconnaissants de bien vouloir nous parler de votre expérience.

Quelles maladies chroniques avez-vous?

- Anxiété
- Arthrite
- Asthme
- Trouble biliaire
- Cancer
- Maladie pulmonaire obstructive chronique (y compris bronchite chronique et emphysème)
- Douleur chronique
- Polyneuropathie inflammatoire démyélinisante chronique (PIDC)
- Maladie de Crohn et colite ulcéreuse
- Dépression
- Diabète
- Épilepsie
- Hépatite C
- VIH/sida
- Lupus
- Maladie de Ménière
- Sclérose en plaques
- Migraines
- Maladie de Parkinson
- État de stress post-traumatique
- Abus d'alcool ou d'autre drogue

Autres maladies – veuillez préciser

2

Quelles sont selon vous les maladies qui ont le plus d'impact sur vos activités quotidiennes? (En choisir une seule)

Je n'ai qu'une maladie et c'est

J'ai plusieurs maladies qui ont un impact sur mes activités quotidiennes, en particulier :

3

Incapacités épisodiques

3. Nous aimerions maintenant vous poser quelques questions sur la nature de l'impact.

Nous souhaitons maintenant savoir quel est l'impact de votre/vos maladie(s) sur vos activités quotidiennes, en termes de prévisibilité, fréquence et intensité.

Lequel de ces énoncés décrit le mieux l'impact de votre/vos maladie(s) sur votre capacité à faire vos activités quotidiennes?

- C'est semblable d'un jour à l'autre
- Cela change de façon imprévisible

Est-ce que votre capacité de faire vos activités quotidiennes

- s'améliore
- empire
- reste la même
- est trop variable pour choisir une de ces réponses
- préfère ne pas répondre

Combien d'épisodes avez-vous eu au cours des 12 derniers mois qui ont affecté votre capacité de faire vos activités quotidiennes?

En général, combien de temps durent ces épisodes?

- Moins d'un jour
- 1-2 jours
- 3-7 jours
- 8-14 jours
- 15-30 jours
- Plus d'un mois
- Incapable de choisir une réponse car leur durée est trop variable
- Préfère ne pas répondre

4

Incapacités épisodiques

4. Impact — Suite

Si vous pensez à vos différents rôles dans votre vie...

... à quelle fréquence est-ce que votre/vos maladie(s) affecte(nt) votre capacité de faire un travail rémunéré ou de travailler pour une entreprise?

- Jamais
- Rarement
- Parfois
- Souvent
- Toujours
- C'est à cause de ma/mes maladie(s) que je ne travaille pas
- Je ne travaille pas pour des raisons indépendantes de ma/mes maladie(s)
- Préfère ne pas répondre

..... votre rôle de parent?

- Jamais
- Rarement
- Parfois
- Souvent
- Toujours
- C'est à cause de ma/mes maladie(s) que je n'ai pas d'enfant
- Je n'ai pas d'enfant pour des raisons indépendantes de ma/mes maladie(s)
- Préfère ne pas répondre

.... votre rôle de conjoint(e)/partenaire?

- Jamais
- Rarement
- Parfois
- Souvent
- Toujours
- C'est à cause de ma/mes maladie(s) que je ne suis pas en couple
- Je ne suis pas en couple pour des raisons indépendantes de ma/mes maladie(s)
- préfère ne pas répondre

.... votre capacité d'aller en cours/de suivre une formation?

- J'ai fini mes cours/ma formation
- Jamais
- Rarement
- Parfois
- Souvent
- Toujours
- C'est à cause de ma/mes maladie(s) que je ne vais pas en cours/je ne suis pas de formation
- Je ne vais pas en cours/je ne suis pas de formation pour des raisons indépendantes de ma/mes maladie(s)
- Préfère ne pas répondre

.... votre capacité de faire du bénévolat ou de participer à des activités communautaires?

- Jamais
- Rarement
- Parfois
- Souvent
- Toujours
- C'est à cause de ma/mes maladie(s) que je ne fais pas de bénévolat
- Je ne fais pas de bénévolat pour des raisons indépendantes de ma/mes maladie(s)
- Préfère ne pas répondre

.... votre capacité de prendre soin d'autres personnes?

- Jamais
- Rarement
- Parfois
- Souvent
- Toujours
- C'est à cause de ma/mes maladie(s) que je ne prends pas soin d'autres personnes
- Je ne prends pas soin d'autres personnes pour des raisons indépendantes de ma/mes maladie(s)
- Préfère ne pas répondre

.... votre capacité de participer à des activités récréatives passives comme lire, regarder la télévision , etc?

- Jamais
- Rarement
- Parfois
- Souvent
- Toujours
- C'est à cause de ma/mes maladie(s) que je ne participe pas à des activités récréatives
- Je ne participe pas à des activités récréatives passives pour des raisons indépendantes de ma/mes maladie(s)
- Préfère ne pas répondre

.... votre capacité de participer à des activités physiques/sportives?

- Jamais
- Rarement
- Parfois
- Souvent
- Toujours
- C'est à cause de ma/mes maladie(s) que je ne participe pas à des activités physiques/sportives
- Je ne participe pas à des activités physiques/sportives pour des raisons indépendantes de ma/mes maladie(s)
- Préfère ne pas répondre

7

Incapacités épisodiques

5. Nous aimerions maintenant en savoir plus sur votre expérience professionnelle.

Laquelle des descriptions suivantes correspond le mieux à votre situation actuelle en matière d'emploi? Êtes-vous...

- à votre compte
- employé(e) à plein temps (30 heures ou plus / semaine) **et** mon emploi est permanent
- employé(e) à plein temps (30 heures ou plus / semaine) **et** mon emploi est saisonnier
- employé(e) à plein temps (30 heures ou plus / semaine) **et** mon emploi est pour une durée déterminée/contractuel
- employé (e) à temps partiel (moins de 30 heures / semaine) **et** mon emploi est permanent
- employé (e) à temps partiel (moins de 30 heures / semaine) **et** mon emploi est saisonnier
- employé (e) à temps partiel (moins de 30 heures / semaine) **et** mon emploi est pour une durée déterminée/contractuel
- mis(e) à pied temporairement
- à la recherche d'un emploi
- pas en recherche d'emploi mais capable de travailler
- à la retraite
- complètement incapable de travailler à cause de ma/mes maladie(s)
- ne sait pas / préfère ne pas répondre

Incapacités épisodiques

6. Votre expérience professionnelle — Suite

Avez-vous déjà travaillé?

- Oui
- Non
- Préfère ne pas répondre

Incapacités épisodiques

7. Votre expérience professionnelle — Suite

Quand avez-vous travaillé pour la dernière fois?

Pour quelle(s) raison(s) avez-vous arrêté de travailler?

- À cause de ma santé
- Pour des raisons autres que ma santé
- Préfère ne pas répondre

Autre (veuillez préciser)

Incapacités épisodiques

8. Votre expérience professionnelle — Suite

En moyenne, combien d'heures travaillez-vous par semaine?

- 1-9 heures
- 10-19 heures
- 20-29 heures
- C'est trop variable d'une semaine à l'autre pour donner une moyenne
- Préfère ne pas répondre

Incapacités épisodiques

9. Quelques précisions sur votre emploi actuel

Quand avez-vous commencé cet emploi?

Dans quelle mesure êtes vous certain(e) d'encre avoir cet emploi dans deux ans

- Très certain(e)
- Assez certain(e)
- Pas certain(e) du tout
- Préfère ne pas répondre

Incapacités épisodiques

10. Votre expérience professionnelle — Suite

Pendant vos épisodes de maladie, êtes-vous capable de travailler?

- Oui, je peux faire mes heures normales
- Oui, mais je dois réduire mes heures
- Des fois oui, d'autres non
- Non, je ne suis pas capable de travailler
- Préfère ne pas répondre

Incapacités épisodiques

11. Votre expérience professionnelle — Suite

Quel travail faites (faisiez)-vous? *Veillez répondre le plus précisément possible –par ex. enseignante au secondaire, vendeur dans un magasin, plombier.*

C'était (c'est) dans quel type d'entreprise, d'industrie ou de service? *Veillez répondre le plus précisément possible – par ex. police municipale, magasin de détail, gouvernement fédéral.*

Avez-vous accès à des prestations complémentaires d'assurance-maladie?

- Oui
- Non
- Préfère ne pas répondre

Incapacités épisodiques

12. Et maintenant, une question sur vos prestations complémentaires d'assurance-maladie?

Avez-vous une assurance-maladie complémentaire? *Cocher toutes les réponses qui conviennent.*

- Prestation d'invalidité à court terme
- Prestation d'invalidité à long terme
- Couverture des médicaments sur ordonnance
- Couverture des soins dentaires
- Couverture d'autres soins médicaux professionnels — physiothérapeute ou chiropraticien par ex.
- Préfère ne pas répondre

Autre (veuillez préciser)

Incapacités épisodiques

13. Et

Combien d'emplois avez-vous eu au cours de la dernière année?

- Aucun
- 1 seulement
- 2-5
- 6 ou plus
- Préfère ne pas répondre

Incapacités épisodiques

14. Et, au sujet de vos emplois multiples.....

Pour quelle(s) raison(s) avez-vous eu de multiples emplois? (Cocher toutes les réponses qui conviennent.)

- J'ai changé d'emplois à cause de mes problèmes de santé
- C'était des emplois contractuels/occasionnels/pour une durée limitée
- Préfère ne pas répondre
- Autre (veuillez préciser)

Incapacités épisodiques

15. Votre expérience professionnelle - Suite

Vos maladies vous ont-elles amené(e) à changer le type de travail que vous faites?

- Oui
- Non
- Préfère ne pas répondre

Vos maladies vous ont-elles amené(e) à changer la quantité de travail que vous faites?

- Oui
- Non
- Préfère ne pas répondre

Vos maladies vous ont-elles amené(e) à changer d'emploi?

- Oui
- Non
- Préfère ne pas répondre

Au cours des cinq dernières années, vos maladies vous ont-elles amené(e) à faire du télétravail ou à travailler depuis chez vous?

- Oui
- Non
- Préfère ne pas répondre

Est-ce que votre emploi actuel (ou votre dernier emploi si vous ne travaillez pas) vous permet de mettre à profit la totalité de votre éducation, votre formation et vos compétences?

- Oui
- Non
- Préfère ne pas répondre

Est-ce que votre emploi actuel (ou votre dernier emploi si vous ne travaillez pas) nécessite le niveau d'éducation que vous avez?

- Oui
- Non, je suis/j'étais sous-qualifié(e) pour mon emploi actuel/dernier emploi
- Non, je suis/j'étais surqualifié(e) pour mon emploi actuel/dernier emploi
- Préfère ne pas répondre

Est-ce que votre employeur actuel (ou votre dernier employeur si vous ne travaillez pas) est/était au courant de vos problèmes de santé?

- Oui – il est/était au courant de mes problèmes de santé
- En partie — je n'ai pas divulgué toutes mes maladies
- Non – Je n'ai/avais pas indiqué que j'ai/avais une/des maladie(s)
- Préfère ne pas répondre

Incapacités épisodiques

16. Et, au sujet de ces maladies...

Quelle(s) maladie(s) n'avez-vous pas divulgué(e)s?

20

Incapacités épisodiques

17. Et, au sujet de votre employeur...

Dans quelle mesure avez/aviez-vous le soutien de votre employeur pour votre/vos maladie(s)?

- Beaucoup de soutien
- Un peu de soutien
- Aucun soutien
- Préfère ne pas répondre

21

Incapacités épisodiques

18. Et, au sujet de vos collègues...

Est-ce que vos collègues sont/étaient au courant de vos problèmes de santé?

- Oui, **tous** mes collègues étaient au courant de **toutes** mes maladies
- En partie, **tous** mes collègues étaient au courant de **certaines** de mes maladies
- En partie, **certaines** de mes collègues étaient au courant de **toutes** mes maladies
- En partie, **certaines** de mes collègues étaient au courant de **certaines** de mes maladies
- Je n'ai/avais pas de collègue
- Non
- Préfère ne pas répondre

Incapacités épisodiques

19. Vos collègues - Suite

Est-ce que cela vous a compliqué la vie au travail?

- Oui
- Non
- Préfère ne pas répondre

Dans quelle mesure avez/aviez-vous le soutien de vos collègues pour votre/vos maladie(s)?

- Beaucoup de soutien
- Un peu de soutien
- Aucun soutien
- Préfère ne pas répondre

Incapacités épisodiques

20. À présent, quelques questions sur les aménagements du travail

Si vous pensez à votre milieu de travail, avez-vous besoins/obtenez vous des aménagements de travail pour vous aider du fait de votre/vos maladie(s)? *Aménagement pourrait faire référence à un support dorsal pour votre chaise, des toilettes accessibles, la redéfinition de vos tâches ou des horaires flexibles. Et si vous ne travaillez pas en ce moment, veuillez répondre pour votre dernier emploi.*

- Non, je n'ai besoin d'aucun aménagement
- Oui, j'ai besoin d'aménagements et j'obtiens tous que je demande
- Oui, j'ai besoin d'aménagement et j'ai obtenu ceux que je demande
- Oui, j'ai besoin d'aménagements mais je n'ai pas demandé à mon employeur
- Oui, j'ai besoin d'aménagements mais mon employeur ne me les a pas fournis
- Préfère ne pas répondre

Incapacités épisodiques

21. Aménagements

Type d'aménagement, obtenu ou non?				
	Pas nécessaire	Reçu conformément à tous les besoins	Reçu en partie seulement	Nécessaire mais pas reçu
Redéfinition des tâches (tâches modifiées ou différentes)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Modification de l'horaire (heures ou jours modifiés ou réduits)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Soutien humain (lecteur, interprète gestuel, tuteur au travail ou assistant personnel)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Aides techniques (synthétiseur vocal, télétype ou ATS, système infrarouge ou appareil portatif de prise de notes)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ordinateur avec Braille, affichage en gros caractères, reconnaissance vocale ou scanner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Aides à la communication (documentation en Braille ou en gros caractères ou appareil enregistreur)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Poste de travail modifié ou ergonomique	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chaise spéciale / support dorsal	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mains courantes / rampes d'accès	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stationnement adapté	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ascenseur accessible	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Toilettes accessibles	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transports accessibles	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Autre (veuillez préciser si vous l'avez obtenu ou non)				
<input type="text"/>				

Incapacités épisodiques

22. Voici maintenant trois questions sur votre perception de la discrimination à votre égard.

Au cours des cinq dernières années, pensez-vous avoir été mis(e) à pied d'un emploi à cause de vos problèmes de santé?

- Oui
- Non
- Préfère ne pas répondre

Au cours des cinq dernières années, pensez-vous qu'on vous a refusé un entretien d'embauche à cause de vos problèmes de santé?

- Oui
- Non
- Préfère ne pas répondre

Au cours des cinq dernières années, pensez-vous qu'on vous a refusé un emploi ou une promotion à cause de vos problèmes de santé?

- Oui
- Non
- Préfère ne pas répondre

Incapacités épisodiques

23. Nous aimerions en savoir un peu plus sur vous.

De quel sexe êtes-vous?

- Féminin
- Masculin
- Préfère ne pas répondre
- Autre (veuillez préciser)

Quel âge avez-vous?

- Moins de 15 ans
- 15 à 24 ans
- 25 à 34 ans
- 35 à 44 ans
- 45 à 54 ans
- 55 à 64 ans
- 65 ans et plus
- Préfère ne pas répondre

Où habitez-vous?

- Terre-Neuve et Labrador
- Île du Prince-Édouard
- Nouvelle-Écosse
- Nouveau-Brunswick
- Québec
- Ontario
- Manitoba
- Saskatchewan
- Alberta
- Colombie-Britannique
- Yukon
- Territoires du Nord-Ouest
- Nunavut
- Préfère ne pas répondre

Dans quel type de communauté habitez-vous?

- Un grand centre urbain (100 000 habitants ou plus)
- Un centre urbain moyen (entre 30 000 et 99 999 habitants)
- Un petit centre urbain (entre 1 000 et 29 999 habitants)
- Une zone rurale (999 habitants ou moins)
- Préfère ne pas répondre

Quel est le plus haut niveau d'études que vous avez atteint?

- Moins que le diplôme d'études secondaires ou équivalent
- Diplôme d'études secondaires ou certificat d'équivalence
- Certificat de compétence ou diplôme professionnel
- Collège, CEGEP ou autre certificat ou diplôme non-universitaire (*autre que les certificats de compétences et diplômes professionnels*)
- Certificat ou diplôme universitaire en dessous du baccalauréat
- Baccalauréat (*par exemple B.A., B.Sc., LL.B*)
- Certificat ou diplôme universitaire au dessus du baccalauréat
- Ne sait pas/Préfère ne pas répondre

Incapacités épisodiques

24. Et à présent trois questions sur votre situation économique

À combien estimez-vous votre revenu personnel total (avant impôts et déductions) pour les 12 derniers mois?

- Aucun revenu personnel
- Moins de 20 000 \$
- 20 000 à 29 999 \$
- 30 000 à 39 999 \$
- 40 000 à 49 999 \$
- 50 000 à 59 999 \$
- 60,000 à 79 999 \$
- 80 000 à 99 999 \$
- 100 000 \$ et plus
- Préfère ne pas répondre

Quel était le revenu total de votre foyer (avant impôts et déductions) ces 12 derniers mois?

- Moins de 20,000 \$
- 20,000 à 29,999 \$
- 30,000 à 39,999 \$
- 40,000 à 49,999 \$
- 50,000 à 59,999 \$
- 60,000 à 79,999 \$
- 80,000 à 99,999 \$
- 100,000 \$ et plus
- Ne sait pas/Préfère ne pas répondre

Est-ce que le revenu de votre foyer suffit pour vos besoins de base?

- Oui
- Non
- Préfère ne pas répondre

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Derniers commentaires

Qu'est-ce que vous trouvez le plus difficile dans votre vie avec une/des maladie(s) chronique(s)

Qu'est-ce qu'on pourrait faire, selon vous, pour améliorer votre qualité de vie?

Y a-t-il d'autres aspects de votre expérience de la vie avec une/des maladie(s) chronique(s) dont vous aimeriez nous parler?

Incapacités épisodiques

25. Merci

Si vous connaissez quelqu'un d'autre qui a une maladie chronique et serait d'accord pour répondre à ce questionnaire, veuillez lui transmettre le lien. Le plus d'information nous recueillons, le plus nous aurons des résultats complets.

Merci beaucoup d'avoir participé à cette enquête.

Si vous souhaitez recevoir un exemplaire de notre rapport, veuillez envoyer un courriel à adfurrie@rogers.com avec votre nom et votre adresse courriel. Nous serons heureux de vous le faire parvenir.

Et maintenant, cliquez sur « Quitter » en haut à droite de la page pour transmettre vos réponses!

